

PROCEEDINGS
Third Annual Conference
of the
Model Reporting Area
for
Blindness Statistics
1964



U.S. DEPARTMENT OF
HEALTH, EDUCATION, AND WELFARE
Public Health Service

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APPENDIX

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
Public Health Service
NATIONAL INSTITUTES OF HEALTH, NATIONAL INSTITUTE OF
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PROCEEDINGS OF THE THIRD ANNUAL CONFERENCE OF THE MODEL REPORTING AREA FOR BLINDNESS STATISTICS

RALEIGH, N.C.

MAY 14-15, 1964

I. INTRODUCTION

The Third Annual Conference of the Model Reporting Area for Blindness Statistics (MRA), sponsored by the National Institute of Neurological Diseases and Blindness (NINDB),¹ in cooperation with the North Carolina State Commission for the Blind, was held on May 14-15, 1964, in Raleigh, N.C. The agenda of the Third Annual Conference was concerned primarily with the progress and development of the MRA, blindness statistics produced from the MRA program, and selected current activities and research on blindness and severe vision impairment which related either directly or indirectly to the Model Reporting Area.

In attendance at the Third Annual Conference were the administrators and blindness register technicians from 9 of the 10 member States, including the State of Oregon which was formally admitted to the MRA at the Conference, representatives from 6 nonmember States, and representatives from various Federal agencies, national and State voluntary agencies, and other institutions concerned with the problem of vision impairment. The MRA States represented were Connecticut, Kansas, Louisiana, Massachusetts, New Jersey, North Carolina, Oregon, Rhode Island, and Vermont. Representatives from New Hampshire could not attend due to unavoidable circumstances. Nonmember States represented were California, District of Columbia, Georgia, South Dakota, Utah, and Virginia. Attending from voluntary agencies were representatives of the American Foundation for the Blind, the National Society for the Prevention of Blindness, the Catholic Guild for All the

Blind, and the Canadian National Institute for the Blind. Federal agencies with blindness programs which were represented at the Conference included the Library of Congress, the Bureau of Family Services of the Welfare Administration, and the National Institute of Neurological Diseases and Blindness. Other agencies and institutions represented were the Russell Sage Foundation, Columbia University, the University of North Carolina, and Gallaudet College.

Dr. Hyman Goldstein, Chief of the Biometrics Branch, NINDB, was Chairman of the 2-day Conference. Dr. Goldstein, speaking for the NINDB and the Model Reporting Area, noted with gratitude the extensive efforts of the North Carolina State Commission for the Blind in its role as host of the Third Annual Model Reporting Area Conference.

Mr. H. A. Wood, Executive Secretary, North Carolina State Commission for the Blind, welcomed the conferees and expressed the pleasure of the Commission in serving as host of the Conference and extended the best wishes of the Commission for a fruitful conference.

II. SPECIAL PRESENTATIONS

- a. Dr. Leo H. Riley, Director of Research, American Center for Research in Blindness and Rehabilitation, presented a paper on "Predictors of Blindness in Diabetes." (See Appendix A for this paper and discussion which followed.) A summary of this paper appears below.

SUMMARY

Dr. Riley stated that preliminary investigations of the diabetic blind at St. Paul's Rehabili-

¹ National Institutes of Health, Public Health Service, U.S. Department of Health, Education, and Welfare.

tation Center for the Blind had not confirmed statements in the literature about relationships between the severity of diabetes and blindness, nor about poor control of diabetes and blindness, nor even about pituitary suppression and blindness. This gave rise to the current research project dealing with diabetes as a cause of blindness.

It was felt that the blind diabetic at St. Paul's might not constitute a valid sample. Therefore, after further consideration and advice, the study was confined to those patients who went to the Joslin Clinic within 1 year of their diagnosis of diabetes. The Joslin Clinic was selected as a source for cases because it was the leading single referral source of blind trainees to St. Paul's. As it was decided to limit the study to blind persons residing in Massachusetts, advantage was taken of the Massachusetts blindness register as a research tool.

After searching and comparing records at the Massachusetts Division of the Blind and the Joslin Clinic, the study population was consolidated to 158 blind diabetics who had gone to the Joslin Clinic within 1 year after diagnosis of diabetes during the period 1930 through 1954. These 158 persons included 83 males of which 43 were living and 40 were dead and 75 females of which 45 were living and 30 dead. A sighted diabetic control was selected for matching with each case according to the following criteria: (1) Date of birth within 5 years of index case, (2) sex, (3) Massachusetts resident at last known address, (4) treated at Joslin Clinic within 1 year of diagnosis of diabetes, (5) living on date of blindness registration of index case.

After all data for the cases and controls are collected they will be analyzed for significant differences between the two groups. This study should indicate information for further research.

In addition to the current study of matched pairs, Dr. Riley indicated that the entire group of blind diabetics at Joslin will be compared with all other Massachusetts diabetics at the Joslin Clinic in an attempt to answer specific questions such as: Does the incidence of blindness in diabetics vary by sex? Does the age at onset divide the study group into two populations, or is there a continuum? Is the delay in diagnosis

of diabetes a factor in blindness? Is the severity of diabetes a factor in blindness?

b. Mr. William D. Simmons, Head, Prevention of Blindness Program, California Department of Public Health, presented a paper on "California Hopes for Coordinated Use of a Register." (See Appendix B for this paper and discussion which followed.) A summary of the paper appears below.

SUMMARY

Not having a statewide register of blind persons, California has, in the past, made use of reportable diseases, annual counts of blind children in public school programs, social characteristics studies of blind aid recipients, and special studies to obtain information on the causes of blindness and the nature of the blind population in California.

Recent inquiries have pointed out the desirability of having a central register for reporting the causes of blindness. First, a State agency requested a figure representing the "universe of operable cataracts." Also, there were requests as to whether or not cases of retrobulbar fibroplasia had again begun to appear. To answer such questions only very rough estimates could be made using the limited available information.

It seems that there is justification for investigating a centralized system for data collection on causes of blindness and characteristics of the blind population in order to avoid duplication of effort and to serve the needs of the several departments and agencies providing services and developing programs. To determine the possibility of initiating a centralized blindness data collection system, a questionnaire was drafted to learn from agencies and organizations serving the blind how and what types of information were collected, how often such information was updated, and in what form the data was kept. Also, the questionnaire was used to determine the completeness of the information, whether or not specific information could be provided from the data being collected, to what uses such a centralized data collection system might be put, and finally to determine the willingness of the various departments to discuss further the

needs for blindness reporting and the possible means for supporting such an operation. Some questions or concerns were raised but the response to the questionnaire was encouraging. All agencies agreed to the usefulness of register information and were willing to discuss the matter further. Preliminary discussions have been held.

According to Mr. Simmons, the most urgently needed information on blindness from the standpoint of control and prevention is epidemiological data. It is on that basis that the State Health Department in California has accepted for the time being the leadership in exploring a reporting system and registration of blindness for coordinated use by several departments in State government.

c. Mr. Richard E. Onken, Research Assistant, American Foundation for the Blind, presented a paper on "Study of Attitudes, Awareness, and Performance of Blindness Reporting Sources." (See Appendix C for this paper.) A summary of the paper appears below.

SUMMARY

Mr. Onken presented a preliminary report on a study to investigate the attitudes, awareness, and performance of blindness reporting sources. The States of Kansas, Louisiana, Massachusetts, New York, Oregon, Ohio, Rhode Island, and Virginia are cooperating with the American Foundation for the Blind in the conduct of the study.

The study will make use of questionnaires to attempt to determine the attitudes of potential reporting sources (i.e., ophthalmologists, EENT specialists, optometrists, blindness agencies, etc.) toward the reporting of blindness to a central register of blind persons. In addition, information will be collected on the uses to which registers are put, on attitudes toward forms being used to report to blindness agencies, and on attitudes toward mandatory reporting.

Results of the study will be utilized to identify and describe problems in blindness reporting. The findings will also be used to improve and facilitate a systematic reporting of blindness thereby making registers more complete, stimu-

lating research in the field of blindness, and providing a basis for a more accurate evaluation of blindness programs.

The study is now in its early stages relating to construction of the questionnaire. Mr. Onken stated that it was hoped that a final report on the study could be presented at the next annual MRA conference.

d. Dr. Eric Josephson, Research Associate, American Foundation for the Blind, presented a paper on "Problems in Studying Blind People." (See Appendix D for this paper.) A summary of the paper appears below.

SUMMARY

One alternative to sampling from State blindness registers is screening a sample of all households in a community to locate cases of visual impairment and blindness. An expensive and complicated process, this is what the American Foundation for the Blind and Western Reserve University did in a recent Cleveland study. One of the primary aims was to determine whether the telephone offers a suitable means of screening health conditions such as visual impairment. Another objective was to discover whether reliable vision tests can be administered in homes by nonmedical interviewers. This was not just a study of legally blind persons. Rather, the investigators adopted the functional criteria for defining visual impairment which have been used by the National Health Survey. The assumption was made that a fairly large sample of households would be essential to find "hidden" cases of blindness, i.e., blind persons unknown to local agencies. Hence, it was decided to rely chiefly but not exclusively on the telephone for screening purposes. The great majority of householders have phones and blind people in Cleveland are as likely to have them as sighted persons.

What was done in Cleveland was to draw a random sample of nearly 3,700 households from the most recent city directory; it split into a telephone sample of approximately 2,800 homes and a nontelephone sample of 900 households (including unlisted numbers). These households were screened over the telephone or in person with a checklist of health items, includ-

ing "serious trouble seeing even when wearing glasses." Interviews were then conducted with all persons reported as having serious trouble seeing and visual acuity tests were administered to them in their homes.

In the study sample the prevalence of reported visual impairment and of blindness as determined by the study vision tests was fairly close to National Health Survey and Hurlin estimates. Although little agreement was found between the results of these study vision tests and what validating physicians reported, the investigators felt that these tests achieved at least one objective—a check against self-reported disability. The interviews with visually impaired respondents provided much data about the impact which trouble seeing has on their lives. Thus, half of them had never received social or medical services. Of the small number of legally blind persons in the study sample, more than half were "hidden" or unknown to the local private agency providing services to the blind.

Because of the expense, it is unlikely that this type of survey will become popular in research on blindness. Therefore, State registers will remain a major source for sampling blind people. To insure that findings will be reliable, any sampling from State registers must be representative of all people being studied. This means that there must be no preselection or prior screening of persons who might fall into the sample. Are such studies an invasion of privacy? Researchers as well as State agencies are committed to protect the anonymity of registered clients; clients themselves, however, should be given the right to decide whether or not they wish to be interviewed. If someone else decides for them, results may be biased.

Among the States a few have been approached more than others with requests for help in doing research based on their registers. This has imposed a burden on these States, but as the Model Reporting Area grows it is likely that this load will be spread more equitably. In any case, research on blindness, both short-range and long-range in scope, should help all agencies providing services to blind people. If this research is to be done successfully, there must be full co-operation between State agencies and those per-

sons engaged in research—which includes people outside as well as inside organizations directly concerned with the welfare of blind people. Given this cooperation, blind people themselves will be the beneficiaries.

e. Dr. Hyman Goldstein, Chief, Biometrics Branch, National Institute of Neurological Diseases and Blindness, presented a paper on "Proposed Pilot MRA Register in Egypt." (See Appendix E for this paper.) A summary of the paper appears below.

SUMMARY

Dr. Goldstein indicated that the Office of International Research, NIH, has mentioned the desirability of establishing a Model Reporting Area blindness register on a pilot study basis in a selected area in Egypt as a Public Law 480 funds project. Contact was made with the Egyptian Government in order to explore this matter. Dr. Goldstein visited that country and outlined a proposed blindness register demonstration project, the objective of which was to ascertain the feasibility of developing and utilizing such register as a mechanism in an underdeveloped country for producing statistics on blindness needed for prevention and control activities. It is planned to incorporate into such a register the standards utilized by the Model Reporting Area for Blindness Statistics in this country. The methodology and procedures to be developed may serve as a model for the Egyptian Government should it desire to make similar efforts in larger geographic units at a later date.

From census data published in the past, it appears that the Egyptian blindness prevalence rate is one of the highest in the world. Such census data, however, are not validated by visual acuity or cause data. It would appear that a registration procedure in Egypt might offer some possibility of validating the blindness data with visual acuity and cause information and thus arrive at meaningful rates to permit a preventive approach.

Meetings were held in Cairo and in Alexandria with various governmental officials and medical scientists. It was agreed that the proposed project be established in a community or district with a population of between 200,000

and 300,000 persons. The site finally selected is in the Governorate (State) of Giza. Included in the population to be studied are some 105,000 urban dwellers and about 167,000 rural dwellers.

The definition of blindness to be used will be one where a person with a visual acuity of 6/60 or worse in the better eye with best correction will be designated "blind." Also incorporated will be a visual field restriction of 20° for vision of better than 6/60. This definition is, in effect, the same one used in the Model Reporting Area. The latest revision of the Standard Classification of Severe Vision Impairment and Blindness will be utilized.

It is expected that the project would run about 3 years. As currently envisaged, there will be three phases to the study. Phase I will constitute a survey of the visual acuity of a randomly selected sample of 10,000 persons of the population selected for study to yield baseline prevalence rates of blindness. Visual acuity examinations using portable visual screeners will be made on a house-to-house basis. Demographic, social, and other data will also be obtained from everyone falling into the sample. Any person in the sample whose visual acuity meets the blindness definition will then be examined by an ophthalmologist in order to obtain cause data. Prevalence rates by age, sex, urban and rural, will be computed. Phase II will be a publicity campaign to get everyone in the project area to come in for a visual acuity test voluntarily at either their local health centers or hospitals. Any person picked up in this voluntary screening as blind will be examined ophthalmologically. In addition, all agencies serving the blind, hospitals, and clinics, will be canvassed to get information on the known blind. The prevalence rates computed from the involuntary or random screening of Phase I will be compared with the voluntary screening prevalence rates of the entire population of Phase II in order to determine which demographic groups are underrepresented in voluntary screening and in order to determine where to focus educational efforts aimed at correcting such underrepresentation. Phase III will constitute a sample survey similar to Phase I. This

will allow a crude measure of net incidence by comparison with the results of Phase I.

Steps will be taken to insure that the reliability of persons doing the vision testing are comparable from tester to tester. Similar steps will be taken with respect to the diagnostic reliability of the ophthalmologist.

III. PROGRESS IN MODEL REPORTING AREA STATES DURING 1963

CONNECTICUT: Mrs. Daley, speaking for Mr. McCollam, who was unable to attend the Conference, stated that at the time of the Second Annual MRA Conference in 1963, Connecticut was still in process of converting its register of some 3,300 blind individuals to an IBM punchcard system. This project was started in January of that year and completed on August 22, 1963. Upon completion of the project Mrs. Daley felt that the effort involved was very worthwhile.

Mrs. Daley noted that they had experienced little difficulty in maintaining the system. Some internal problems had arisen, such as the securing of complete data, but steps had been taken to correct this. However, the securing of full data required on the eye report form continued to be a problem. The two principal items on the form which presented problems were those of etiology and age at onset of severe vision impairment. Mrs. Daley pointed out that these items frequently were not filled out or were marked "unknown." Also, the deletion of the term, "congenital anomalies" from the Standard Classification of Causes of Severe Vision Impairment and Blindness presented considerable coding difficulty to the consulting ophthalmologist when there were many conditions present, any one of which might have been used if clearly identified.

In August 1963 a brief letter was mailed to ophthalmologists and eye-ear-nose-and-throat specialists enclosing the most recent report of the agency and the latest eye report form, as well as the brochure on the purpose and program of the Model Reporting Area. The MRA tabulations for 1963 (submitted in February 1964) made it possible to furnish an additional set of statistics to the ophthalmologists showing the

incidence and causes of blindness during 1963, including a tabulation on type of affection. It was hoped that by more frequent contacts with ophthalmologists existing problems might be adjusted or overcome.

Mrs. Daley further indicated that her agency was having difficulty in meeting the February 15 deadline for submission of tabulations. She indicated that to obtain the necessary data on cases referred just prior to December 31, at least 2 weeks were required to obtain and evaluate the data necessary for the proper coding of those cases and inclusion in the count for the year. With the normal delays that were apt to be incurred, at least a month was required for the processing of the material and the production of the tables. Mrs. Daley felt that the February 15 deadline was too early to permit proper review of the tabulations by her agency. She therefore suggested that the closing date for submitting tabulations be March 15 or, at the earliest, March 1.

KANSAS: According to Mr. Grabhorn, the Model Reporting Area program in Kansas has not only received the full support from the Director of the blindness agency, but from the State Director of Public Welfare and the State Board of Public Welfare as well.

Mr. Grabhorn believed the problems in Kansas were similar to those found in other States; that is, getting full, complete, and appropriate information about persons on the register and locating and registering blind persons previously unknown to the blindness agency.

Mr. Grabhorn indicated that a close rapport exists between the State and county welfare departments. Nevertheless, his agency had made great efforts to gain even fuller cooperation with the county departments of welfare and the county social workers who helped to gather information on the registrants and to update the register. As an illustration of how this was being accomplished, Mr. Grabhorn noted that his agency had been participating in meetings such as the social service training meetings, at which time Kansas' participation in the Model Reporting Area was stressed and cooperation from persons attending the meetings was solicited. When calling upon blind persons in Kansas, the county social workers are urged to rep-

resent themselves as part of a team working in cooperation with MRA States in updating the blindness register. Mr. Grabhorn felt that in making calls on blind persons in their communities, the social workers could offer the opportunity of sharing information about their blindness and social situation and, possibly, could be of service.

Mr. Grabhorn noted that information about the MRA is included in the agency's Manual of Operations which is available to all social workers. Also, the MRA blindness statistics are made available to social workers and others. These steps have all proven to be effective in helping to maintain an updated register.

Miss Blase reported that she believed the real progress in Kansas during the past year was the cooperation her agency was getting from the ophthalmologists in reporting not only blindness, but supplying sufficient information for coding purposes. She also mentioned that her agency was in very good accord with the optometrists. Ophthalmological information was obtained on over 90 percent of the people reported as blind. Where ophthalmological information is not initially reported, a followup is made with good results. Ophthalmologists throughout the State are kept informed of agency activity and MRA blindness statistics have been sent to them.

Miss Blase mentioned that the State ophthalmologist was enthusiastic about the MRA program and, in addition, was responsible for doing the medical coding from the eye report forms.

Miss Blase felt that the big job during the next year was to proceed in the updating of the blindness register.

Mr. Grabhorn stated that Kansas had benefited from a wide-area telephone service which enables the blindness agency to reach and communicate with persons throughout the State at almost any time. This service makes it possible to get information quickly and easily and to communicate better not only with ophthalmologists but also with clients and county social workers.

LOUISIANA: Mr. Bridges reported that Louisiana had completed a thorough updating of its register in accordance with the Model Reporting Area program. In so doing, the total

number of registrants had decreased from approximately 7,500 to approximately 5,500 due to clearance procedures. The parish offices within the welfare department had been very cooperative in working with Mr. Bridges' staff in updating and tracking down those registrants of unknown status. A complete review and recoding of information on each individual was involved in the updating effort.

It was Mr. Bridges' opinion that it would actually be 3 or 4 years before Louisiana would have a good working register because it would take at least that long before techniques were perfected and the "deadwood" cleared out of the register. He indicated that determining the status of some individuals who were not contacted for many years involved a great deal of work and expense. Mr. Bridges believed that the clearing and updating of the register was very important in order to expand and provide services to blind people.

To attempt to obtain the cooperation from the ophthalmologist, Mr. Bridges plans to send out a letter to each ophthalmologist with a copy of the Model Reporting Area brochure and other information informing the ophthalmologists how his agency can be of benefit to blind persons. He thought it would be advisable for his supervisory ophthalmologist to present the program at a meeting of the State Academy of Ophthalmologists.

Miss Ford elaborated on the procedures used to locate registrants and particularly the difficulties in locating elderly blind persons who had moved into low-cost housing projects. She noted that many old persons were found to have had successful cataract surgery since their last contact. Miss Ford mentioned the work with parish offices and the rehabilitation center in gaining information on elderly registrants. As a result of the work in the rehabilitation center, doctors were more conscious of the services offered by the blindness agency and had in turn begun referring blind persons to the agency.

Miss Ford mentioned that blind persons without progressive conditions are requested periodically to obtain new eye examinations.

MASSACHUSETTS: Mr. Sullivan read a progress report prepared by Mr. Mungovan, Director of the Massachusetts Division of the

Blind, who was unable to attend the Conference. He stated that the Division decided to eliminate its usual fiscal year tabulations and combine the tabulations with those on a calendar year basis as required by the MRA. Mr. Sullivan indicated that it was impossible with current staffing to make the count twice a year. As a result the annual census by mail will be made in the fall months rather than in the spring months as in the past.

The Division hoped to work during the summer on updating the register cards as to the discipline of the practitioner who made the last eye examination, changes in visual acuity, and the recording of race of the registrant. This should result in fewer "unknown" in the Massachusetts tabulations. Mr. Sullivan stated that actually there were very few cases for which race was unknown but it was not routinely recorded on the register card because until the MRA, it was of no importance to the Division. Less than 3 percent of the State's population are nonwhite. The Division plans to convert from McBee Keysort cards to IBM punchcards, probably within the next 2 or 3 years. A major problem is a shortage of personnel.

Mr. Sullivan stated that an important problem facing the Division was that of preserving the right of blind people to privacy. Since it had become better known that the Division has a fairly accurate register of the blind there have been increasing requests from various groups for certain information which the Division thought might interfere with the rights of the blind registrants. For example, the Registry of Motor Vehicles had asked the Division to supply it with names of registrants to be matched against the Registry's file so that licenses of blind persons might be suspended. Previously the Division for the Blind had refused to give this information and, in the near future, will hold a conference with the registrar of Motor Vehicles in order to determine some legal way to inform the Registry when a person becomes blind other than using the register of the blind as the informant. The Division felt that it would be better for the physician to report the information directly when, in his judgment, the person should not drive regardless of the legal definition of blindness. Also, the Division

thought another remedy to the problem of visually handicapped automobile operators would be periodic eye examinations as are required in several States.

Other problems concerning the Division related to the conduct of research projects on blindness. Mr. Sullivan described how two requests for utilization of the register in research studies caused the Division some difficulty. Both projects were concerned with interviews with blind persons and this raised the problem of maintaining the privacy of blind persons. Also, in one project, there appeared to be a deviation from the original scope of study. Mr. Sullivan indicated that although the Division was willing to cooperate in research studies that did not violate the privacy of blind persons, it was essential that all details of the study be reviewed in advance with the Division in order to avoid excessive demands on the time and efforts of its limited staff and to prevent any difficulties or embarrassments after the study was initiated.

Mr. Sullivan concluded by stating that operating a register of blind persons is beset with many such problems and that participation in the Model Reporting Area also created some burden. However, when one sees tabulations of data obtained from reports of the Model Reporting Area States it looks as though this effort would prove worthwhile.

NEW HAMPSHIRE: Due to unavoidable circumstances, New Hampshire was unable to send a representative to the Conference. However, Mr. Carl Camp, Supervisor, Services to the Blind, Division of Welfare, New Hampshire Department of Health and Welfare, submitted a progress report by mail to the Biometrics Branch, National Institute of Neurological Diseases and Blindness. A summary of this report follows.

During the past year New Hampshire had experienced both progress and problems within the Model Reporting Area.

The person in charge of coding the register cards in New Hampshire has used each new revision of the Standard Classification of Causes of Severe Vision Impairment and Blindness for cases which were new when the Classification was current. The result has been that when New Hampshire attempted to tabulate its data

from the total register the same item has had various code numbers depending on the date the case was added to the register. This has created considerable confusion in the etiology and type of affection tables, particularly in items where the numbers for various eye conditions were completely reversed, such as the switch of codes between optic nerve atrophy and optic neuritis.

With help from the National Institute of Neurological Diseases and Blindness, New Hampshire plans to recode the entire register under one uniform classification. When achieved, this will speed the tabulation work considerably.

The Division of Reports and Analysis has had one member of its staff loaned to the auditing unit. At the same time the Bureau of Family Services had set up quality control reporting. Therefore, three people in Division of Reports and Analysis were doing the work of four with a few extras added. Furthermore, federal mandatory reports were given priority by the Division of Reports and Analysis over voluntary reporting, such as the Model Reporting Area tables.

The State Department of Health and Welfare had also been in the process of reorganization and moving which had further delayed the work.

Circumstances beyond the Department's control had prevented active participation of its staff in the annual Model Reporting Area meetings. All concerned were confident, however, that New Hampshire would be able to be present in Bethesda in 1965 and take a more active part as a charter member of the Model Reporting Area.

New Hampshire looked forward to the day when its entire register will have been reclassified according to the new Standard Classification of Causes of Severe Vision Impairment and Blindness. New Hampshire is also seriously exploring the possibility of placing its blindness register on IBM cards so that reporting will be expedited. New Hampshire is pleased to be a part of the MRA which it feels will make a major contribution to blindness statistics. The State expects to give as much to the Model Reporting Area as it hopes to receive.

NEW JERSEY: Mr. Meyer mentioned that over the past years a major problem in New Jersey has been the processing of the IBM punchcards. That problem has now been somewhat alleviated by the establishment of a centralized machine tabulating section, which has promised to bring the New Jersey punchcards up to date every 2 months.

Mr. Meyer indicated that he very strongly supported national and regional statistics concerning the blind and felt very encouraged by the participation of the MRA membership. He hoped that not only would the Model Reporting Area rapidly develop a nationwide participation in the project, but also that the Model Reporting Area project would tie in with other interests concerning characteristics of the blind population.

As a result of a recent meeting of the Commission's regional staff certain socio-economic data were being considered for inclusion on the IBM punchcards. It was not certain whether the information would be included on the existing punchcards or a new punchcard started for each registrant.

At the beginning of the MRA project in New Jersey, there apparently was not the enthusiasm among Mr. Meyer's staff for which he had hoped. However, now that the register has been improved as a result of the MRA, and statistical reports are being produced, Mr. Meyer felt that the Educational Service, Rehabilitation Service and Home Service have all become quite interested in the project because each of the services needs reliable statistics on which to base its programs.

NORTH CAROLINA: In reporting on the Commission for the Blind's progress, Miss Anderson noted that it had completed the revision and updating of its register in 1963. She also noted that a new eye report form for the legally blind was released by the Commission's State Supervising Ophthalmologist to all ophthalmologists and eye-ear-nose-and-throat specialists in North Carolina in December 1963.

A covering letter went out from the supervising ophthalmologist with the eye report in which he expressed appreciation for the interest and efforts given the program of the Commission by the ophthalmologists and eye-ear-nose-

and-throat specialists. Dr. Hicks stated that the Commission was making new efforts to increase the services to the visually handicapped and that special interest was being focused upon accumulating data relative to the effects and chief causes of blindness in North Carolina. Dr. Hicks asked them to review the report and give him their impressions and comments. Miss Anderson reported that the comments received from the physicians were very reassuring and positive. A frequent comment was that the report was quite detailed and very long; yet, the physicians felt this was necessary if the Commission were to collect meaningful data. Miss Anderson related to the conferees a few excerpts from the physicians' replies. She reported that the new eye report form had been released for use in the Commission's clinics and a supply of the reports had been sent to each ophthalmologist and eye-ear-nose-and-throat specialist. Miss Anderson felt that in another year the eye report forms would provide the Commission with the information it needs for its register of the blind.

The application form for the Aid to the Blind program was found to be insufficient and was therefore revised during 1963 to provide all the information that was not obtained on the eye report form.

The Commission plans to feed back information such as the MRA statistical reports to the ophthalmologists as well as to the counties and to its own staff. Miss Anderson was certain that the feedback of information would be helpful in creating more interest on the part of the ophthalmologists. As an example of feedback Miss Anderson mentioned that the Commission was making listings of its registrants by county and making the listings available through its field representatives to the ophthalmologists and eye-ear-nose-and-throat specialists in the various counties.

To alleviate somewhat the concept of invading privacy, the Commission had developed a pamphlet called "Services for the Blind in North Carolina" which described its program and assistance. Miss Anderson felt that the Commission had not yet invaded privacy and it did not intend to do so.

Mrs. McColm described a research activity undertaken by the Commission. She indicated that a roster of glaucoma cases was established in North Carolina in the fall of 1962. The roster was established for the purpose of studying possible variations in the incidence of glaucoma, according to such factors as sex, race, age, and geography.

The State of North Carolina consists of 100 counties which are served by 6 district offices. All but one of these district offices began collecting data on glaucoma cases in October 1962. In the five district offices in which data on glaucoma cases were collected there was a total of 1,705 glaucoma cases on the roster in 1962. The corresponding figure for 1964 was about 2,184 cases. The total for all six districts in 1964 was 2,723.

For a few of the districts, Mrs. McColm presented data by sex, race, and age.

When the data were analyzed according to the State's three major geographical regions, namely, the mountain region, the central or Piedmont region, and the coastal region, there seemed to be a trend toward more glaucoma cases in the coastal and mountain areas, with a slightly larger number of cases in the coastal region.

Mrs. McColm pointed out that the study of the incidence of glaucoma had only just started and that more data needed to be collected and studied before any definitive statement on trend or degree of incidence could be made. Mrs. McColm concluded by stating that the dietary and socioeconomic background of the glaucoma cases would also be studied.

OREGON: Mr. Stocker stated that Oregon was very proud to have been accepted as a member of the Model Reporting Area. He felt that this was a goal to which every State should aspire if it were to carry on a professional job of work for the blind. Mr. Stocker commented that Oregon has very good working relationships with the approximately 70 ophthalmologists in the State, but had some work to do in soliciting the cooperation of the optometrists. The Commission requires eye reports from ophthalmologists before providing services.

In Oregon, the total number of registrants on the register was approximately 500-800 fewer

than Dr. Hurlin's estimates for the State. Mr. Stocker believed that the actual count on his register was a more accurate picture of the blind population in Oregon.

Oregon plans to update its register in the fall of each year and in doing so it plans to make use of the State Department of Education, the State School for the Blind, the Elks Club Eye Clinic at the Oregon Medical Center, the Talking Books Machine Service, Department of Public Welfare, Department of Public Health, and the Department of Ophthalmology at the Oregon Medical School. These groups are also good sources for referring blind persons for services.

A problem noted by Mr. Stocker was the location of blind persons who were unwilling to admit that they were blind. He believed that this was another point of education the blindness agency had to get across.

Mr. Stocker was convinced that it was going to cost more money to maintain an accurate register, but he was thoroughly convinced that it was worth it in terms of the benefits derived from an accurate up-to-date register.

RHODE ISLAND: Miss DeTomasso reported that Rhode Island was fully engaged in carrying through the ongoing responsibilities of the MRA program, having completed the original project of revising and updating its register in August 1963. The services of a medical social worker and an additional clerical person enabled Rhode Island to complete the project in an efficient and up-to-date manner.

As a result of close working relationships with the research and statistical unit within the Rhode Island Department of Social Welfare, a system was devised to feed through raw data at certain intervals of time, thereby creating a smooth working process. Several meetings were held between the Division of Services for the Blind and the Research Unit after the initial agreement to implement a system. This helped the Division to check any transposition errors and to keep abreast of time allotted for specific tasks in the program. As a consequence of this process, the Division learned that drawing off raw data on at least a quarterly basis seemed to facilitate operations of both operating units.

Miss DeTommaso noted that after tabulating the required data for the MRA, the statistical data and certain additional information were utilized for two additional separate studies, one for the Rehabilitation Council (a newly formed health agency unit in the State) and the other for the Rhode Island Department of Health, to be used in a neurological and sensory disease study entitled "Vision Survey." The additional data consisted of separation of the following factors: Cause of blindness and age of all blind persons on the Rhode Island register, source of referral, education and age, living arrangements, marital status, and other disorders in addition to blindness.

The Model Reporting Area statistical data were most helpful in the incorporation of information pertinent to the Rhode Island report to the State and Federal governments. Many of the tabulations forwarded to the Biometrics Branch were used without alteration in the Rhode Island annual report.

Miss DeTommaso reported that an additional study was made of retrolental fibroplasia cases reported to her agency during the past 20 years for the retrolental fibroplasia program of the Massachusetts Eye and Ear Infirmary.

Supervisors in the Division's program utilized tabulated data to complement information needed during the intake process, referrals to workers, and caseload management. In turn, Social Services in the Division instituted a paid medical diagnosis program for clients under age 14 and over age 65. The information acquired from this endeavor led to more intensive case work, further medical diagnosis, and toward physical restoration of those youthful and aged clients. Miss DeTommaso noted that progress during the past year had proven to be successful in relation to updating the Division's former register, assisting other organizations with studies, motivating the Division to invent a smooth system of data processing, providing insight into client workload management, making graphic representation to legislators, and assisting the Division to better determine the future structure, design, and progress of its services to blind individuals.

As a final note, Miss DeTommaso added that her Division had adopted the use of the new

NSPB ophthalmological eye report form and ophthalmologists were pleased with it. In addition, an MRA manual for staff members was compiled to familiarize the total staff of the program, procedures, and use of various forms.

VERMONT: Miss Cole reported that Vermont Division of Services to the Blind had completed the revision and updating of its register. Also, it had adopted the new NSPB eye report form and had provided these forms to the rehabilitation and family service programs so that only one eye report form was being used throughout the State.

Regarding the updating of the register, Miss Cole noted that her Division had sent out approximately 600 query letters trying to obtain missing information. She found that the device most successful in obtaining complete information was to print the word "PLEASE" in large red letters at the top of the query letter. According to Miss Cole, the medium of monthly newsletters was very helpful in getting out information to people and helping them to know what the Division was working toward. The Division personnel daily scanned the newspapers and checked with Family Service for register information in addition to securing information supplied by field representatives.

In Vermont the register is divided into two parts, one part containing persons on the MRA register and the other part a "pending" file, including cards which did not have complete information but represented persons with whom the Division was working. The register was being used as a tool for providing service as well as coordinating family services and public assistance. Further, the register was being used to determine weaknesses in the programs as well as to chart trends from year to year.

Miss Cole mentioned that she had designed a folder which indicated in red on the inside the name and address of her Division and contained information on services available to blind people. Miss Cole had sent one of these folders to every ophthalmologist and eye-ear-nose-and-throat specialist in the State as a device for giving information of the services available to blind people and in turn to stimulate referral of blind people to her Division.

Miss Cole mentioned some of the problems which her agency had faced. Some of the Vermont registrants had had several different eye examinations over a period of years and in some cases different doctors had given different diagnoses. Another problem related to the interests of the Vermont Motor Vehicle Department in obtaining from the Division of Services for the Blind a list of all blind people.

Discussion

Father Carroll opened the discussion with some comments about the importance of adequate statistics in the field of blindness. He noted that despite his 26 years in this field he finds reports such as those given at the Conference to be very meaningful. He has found it gratifying to see that some progress has been made over the years to the point of information which is presently available. Although much work is involved, such as keeping registers up to date, there is a need for so much more in the way of blindness statistics. He continually finds a need for such statistics for various purposes. Many years from now programs such as the Model Reporting Area will be the source of important information on such matters as the causes of blindness, the types of persons affected by this disorder, how affected persons get along, their life expectancy, etc. Father Carroll commented on the need for more information on, and a clarification of, the definition of blindness. He also mentioned the importance of using MRA register information for research and he noted the need for further information on deafness and on the deaf-blind population. He emphasized that there is much need for more information, statistics, and research relating to the problem of blindness.

In response to a question by Mr. Meyer, Mr. Goldberg indicated that the MRA annual statistical reports would be routinely sent to all States, agencies, and institutions interested in the problems of blindness regardless of their participation in the Model Reporting Area.

With reference to Mrs. McColm's comments regarding a relatively high prevalence of glaucoma in coastal regions of North Carolina, Mr. Stocker mentioned that he became aware of sim-

ilar situations in Oregon and he asked whether this was true elsewhere. Mr. Goldberg noted that since county of residence is contained on the register cards and punchcards in the various MRA States, tabulations by county could be done independently by the States and such analyses are planned for the MRA as a whole. He also emphasized that consideration must be given to the composition of the population in coastal regions as compared with inland areas since the incidence and prevalence of glaucoma is largely affected by such factors as the age distribution of the population.

Dr. Goldstein briefly summarized some of the problems discussed by the MRA States. Those problems were the date of the deadline for submission of MRA tabulations, the right of blind people to privacy, and the necessity of adding additional items of information to the requirements of the Model Reporting Area. In discussing the date of submission of the MRA tabulations it was pointed out that it was necessary to have approximately 3 months time after receipt of the State tabulations to edit them and prepare the annual tabulations for presentation at the Annual Conference. It was agreed to keep the February 15 deadline at least for the next year. Dr. Goldstein sympathized with the blind person's right to privacy, but pointed out that sometimes there were overriding needs for data for administrative and research purposes. He believed the two goals could be compromised without endangering either one. It was mentioned that the Biometrics Branch had considered adding other items of information to the MRA requirements such as marital status, education, etc., and that this would be given further consideration during the coming year.

Dr. Goldstein was gratified that although the States had mentioned several problems, each of the States seemed to have great assurance that the problems would be overcome. He also noted Mr. Meyer's emphasis of the desirability for good accurate national statistics, thereby eliminating the necessity for embarrassing guess-work regarding the number and characteristics of blind persons.

IV. PROGRESS IN SELECTED NON-MODEL REPORTING AREA STATES AND CANADA DURING 1963

DISTRICT OF COLUMBIA: Mr. Gambaro reported that a contract had been initiated with the NINDB whereby the District of Columbia was establishing a register of blind persons. It was Mr. Gambaro's opinion that the register would be developed in stages. First, all information required by the MRA and other available information would be obtained from existing records. At a later point in time, a personal contact with all registrants would be made in order to get certain additional information of interest to Mr. Gambaro's agency for such activities as planning services.

One problem Mr. Gambaro wished the Model Reporting Area to consider was that of developing a two-or three-digit code for general physical disabilities that could be used by all the States.

Efforts are being made to obtain mandatory reporting legislation which would afford legal protection to reporting physicians.

GEORGIA: Dr. Jarrell indicated that the need for a register of the blind in Georgia had been apparent for some years. During the past session of the State legislature a resolution requiring the Georgia Department of Rehabilitation to maintain a register of blind persons unanimously passed both the Georgia House of Representatives and the Senate. With the assistance of the Biometrics Branch of the National Institute of Neurological Diseases and Blindness the Department hoped to initiate work by June 1964 toward the development of the register. Dr. Jarrell expressed the belief that the Department of Rehabilitation had the cooperation of the State Health Department, the State Welfare Department, and the medical profession. In addition, in metropolitan Atlanta there was a board of 27 outstanding citizens who were going to cooperate with the Department of Rehabilitation in the establishment of the register. An ophthalmologist is already available for the project on a part-time basis.

Mr. Gaines mentioned that a semblance of a register had been started some years ago in

Vocational Rehabilitation but had not lasted long due to lack of clerical help. However, it did point out the need for a good up-to-date record of all blind people in Georgia, of which Mr. Gaines estimated there were approximately 10,000. Mr. Gaines indicated that with the help and support of the other agencies serving the visually handicapped, it was hoped that a good register of the blind could be developed in Georgia. He noted the importance of reliable national statistics on blindness, the importance of a good register for service program, and the interest of his Department in the MRA program.

SOUTH DAKOTA: Mr. Hanson reported that South Dakota had had a law requiring the maintenance of a register of blind persons for about 20 years. However, the register was very limited in its content. Consequently, the opportunity to improve the register with the assistance of the NINDB was welcomed. Beginning in the fall of 1964 a contract was initiated to revise and update the register in South Dakota. One of the problems favorably resolved was the development of a very good working relationship with the Department of Welfare. In accomplishing this task it was felt that the register would be notified of all applications for blindness assistance benefits. This applied to all visually handicapped persons regardless of whether or not they were legally blind because South Dakota maintains a register which is based on a definition of blindness broader than that required by the Model Reporting Area.

Mr. Konrad noted that a majority of the time spent under the contract was used for gathering data which previously had been unknown. Many of the old register cards contained nothing more than name and address. A 50-to 60-percent response was obtained on the mailing of a questionnaire to blind clients in an effort to obtain additional information. For those persons not returning the questionnaire, the rehabilitation counselors were prepared to make telephone contact or direct contact when necessary.

UTAH: Dr. Hall reported that as a result of a lack of accurate data upon which Utah could

build its program for serving the visually handicapped, his agency had become genuinely interested in the Model Reporting Area. Accordingly, work has begun on revising and updating its register under contract with the National Institute of Neurological Diseases and Blindness. The position of a full-time registrar had been created as well as adoption of an eye report form and a tabulating-type punchcard. Also, a consultant ophthalmologist was employed who will be used to consult in the shaping and directing of the agency programs. A liaison and working relationship had been established with practicing ophthalmologists, with other agencies and institutions serving the visually handicapped, and with other groups who might refer blind persons to the register. The MRA program has been integrated into the operation of the agency which is looking forward to full participation in the program.

VIRGINIA: Dr. Mac Farland indicated that the revision of the Virginia register for the visually handicapped should be completed by November 1964. He did feel, however, that after the revision was completed the total count on this register would be some 3,000 short of previous estimates of visually handicapped persons in Virginia. Like many of the other States, a register had been in operation in Virginia for some time but was lacking in the information it contained.

Dr. Mac Farland noted three advantages of a good up-to-date register which have become evident in the course of revising the Virginia register. First, there was more adequate eye information available for some studies which he had in mind; second, he would have good statistics to use when dealing with the legislature; third, working with the codification of causes of blindness stimulated ophthalmologists to propose the establishment of a special corneal clinic. Dr. Mac Farland felt certain there would be a corneal clinic in his State and that it would be a direct result of the revised register.

CANADA: Miss Houston extended to the conferees the greetings from the Director of the Canadian National Institute for the Blind (CNIB). She reported that the number of blind persons registered with the CNIB as of

March 31, 1963, was 24,694. For 24,605 of those registrants, the Institute's consulting ophthalmologist had completed the coding of the eye reports according to the 1957 NSPB Standard Classification of Causes of Blindness. This information has been prepared for entry onto punchcards.

In addition to the regular annual tabulations by age, data were tabulated on causes of blindness. From this material and supplementary information a report for Canada was completed in the fall of 1963. This report was being used by the consultant ophthalmologist for the preparation of a report to be presented at the Pan-American Ophthalmological Association in October 1964 and at the International Association for the Prevention of Blindness meeting in Vienna in June 1964.

The CNIB, as a matter of routine, now codes all new cases as to the causes of blindness. The Institute will prepare reports on causes of blindness annually for those persons registered during a given year, and it is planned to prepare a 5-year report on the causes of blindness.

A revision was made in the forms used for entering information on services provided to registrants which greatly facilitated preparation of reports on service.

V. ACTIVITIES RELATING TO VISION IMPAIRMENT PERFORMED BY THE BIOMETRICS BRANCH, NATIONAL INSTITUTE OF NEUROLOGICAL DISEASES AND BLINDNESS DURING 1963

a. ASSISTANCE TO STATES AND OTHER ACTIVITIES RELATING TO THE MODEL REPORTING AREA

Irving D. Goldberg, Assistant Chief Biometrics Branch, NINDB.

Mr. Goldberg briefly summarized the activities of the Biometrics Branch in providing consultative and contractual assistance to various States throughout the country directly related to the Model Reporting Area program. He noted that visits were made to each of the Model Reporting Area States toward the latter part of 1963 to explain the MRA tabulations which were to be prepared for 1963 and to advise on

the procedures for their preparation. On these and other visits, and through correspondence or other communications, additional matters of pertinence to the States and the MRA were discussed. Visits were also made to those MRA member States which were under contract with the NINDB for the purpose of improving their respective registers through the installation or improvement of mechanical punchcard systems. Such technical assistance was provided to five States (Connecticut, New Jersey, North Carolina, Rhode Island, and Vermont), all of whom completed work under contract during 1963. This brought to seven the number of MRA States whose registers are on mechanical punchcard systems and Mr. Goldberg felt that the installation of punchcards has been a very fruitful and productive accomplishment of the MRA during 1963.

Mention was also made by Mr. Goldberg that all of those MRA States whose registers were on a punchcard system, sent to the Biometrics Branch a duplicate deck of those punchcards which were used to prepare their respective 1963 MRA annual tables. These cards are being used for additional analyses and for planning future work in the MRA program.

With regard to non-MRA States, Mr. Goldberg mentioned that since the last Annual Conference visits were made to 11 States interested in the MRA program. He also noted that expression of interest or inquiry were received from some other States as well. Of the 11 non-MRA States visited, 7 were for the purpose of active engagement toward improving or establishing statewide registers under contract with the NINDB. Those already under contract include the District of Columbia, New Mexico, South Dakota, and Virginia. Contracts have also been approved for Utah and Nebraska, although the latter State asked for a postponement in the initiation of the work. Negotiations were underway for the initiation of a contract, by July 1964, to establish a register in Georgia. The other non-MRA States visited during the year included Texas, New York, California, and Michigan. All of these visits related to meeting the membership requirements in the Model Reporting Area. However, only for New York State is there anticipation of es-

tablishing a contract for this purpose in the immediate future.

The seven States mentioned above now under contract or soon to be under contract would give the MRA a State coverage representing some 22 percent of the country's population. Mr. Goldberg noted that the communications maintained during the year with Oregon resulted in its admission to the Model Reporting Area at this Annual Conference.

Finally, Mr. Goldberg mentioned that the Branch's Medical Record Librarian visited two States under contract in order to train their personnel in the use of the Standard Classification of Causes of Severe Vision Impairment and Blindness.

Discussion

Mr. Meyer asked about the extent to which projections might be made of statistics from the MRA States (including those now under contract) to the United States as a whole. Mr. Goldberg noted that with the addition of the States now working toward membership the Model Reporting Area will have a rather broad geographic coverage, including the New England States, the Middle Atlantic States, the South, the Midwestern section of the country, and representation on the Pacific coast. Nevertheless, he pointed out that despite this broad coverage the Model Reporting Area will not be representative of the United States in the true sense, and he felt it would not be wise to make any projection to the country as a whole because certain very important sections of the country or segments of the population are unrepresented in the MRA program. With the inclusion of such States as New York, California, and Ohio one would be in a better position to project the MRA statistics to national estimates. Membership in the MRA does not constitute a scientifically selected representative sample of the country so that some caution must be exercised in any attempts at projection of the MRA data.

b. RESEARCH ACTIVITIES

1. Study of Association Between Factors of Pregnancy, Labor and Delivery and the Occurrence of Blindness in Children

Irving D. Goldberg, Assistant Chief,
Biometrics Branch, NINDB.

Mr. Goldberg stated that the study of association between factors of pregnancy, labor and delivery, and the occurrence of blindness in children was initiated by the Biometrics Branch early in 1962. Summaries of the status and progress of the study may be found in the Proceedings of the First and Second Annual Conferences of the Model Reporting Area. He noted that the study was initiated because of the relatively high proportion of blindness in children which appeared to be due to unspecified prenatal factors. The objective of the study is to determine whether mothers of blind children are characterized by an excess of selected prenatal and perinatal disorders as compared to mothers of the total population of live births surviving the neonatal period (that is, surviving the first 28 days of life). The case group of children was obtained from the blindness register maintained by the New York State Commission for the Blind, the study being confined to New York State.

The study comprises just under 600 blind children born in New York State during the period 1948 through 1960 inclusive, who were classified blind due to reasons of unspecified prenatal or genetic causes. The control group against which cases are to be compared is a stratified sample of three in every one thousand recorded live births surviving the neonatal period during the 13-year study period in New York State. This control group comprises approximately 13,000 births. Data pertaining to conditions of pregnancy, labor, and delivery for both cases and controls were obtained from the confidential medical supplements of the respective birth certificates.

Machine tabulations for the New York City portion of the study have been prepared and are in the process of being analyzed. Tabulations for the rest of New York State are now in the process of being prepared and should be available for analysis in the immediate future.

Mr. Goldberg noted that only limited data were available from the New York City portion of the study at this time but there was some indication of a positive finding for at least one of the factors on the study, namely birth weight. However, he did not wish to go into any detail

regarding this matter until more data became available. Mr. Goldberg stated that the study should be completed by the end of the year and it was his hope that a complete report could be made of the findings at the next Annual Conference of the Model Reporting Area.

Discussion

Mr. Stocker inquired as to whether a member State could call upon the Biometrics Branch for assistance in the design of a study utilizing its register data. Mr. Goldberg replied that this was one of the reasons for establishing the Model Reporting Area program. Specifically, one of the objectives of the MRA is to stimulate research in the field of blindness. To reach its maximum potential the register should serve a dual purpose, namely, to provide services to individuals and to utilize the information contained in its register for statistical and research purposes. Mr. Goldberg mentioned that any States interested in the conduct of any research, and who wished the assistance of the Biometrics Branch in planning and conducting such research, should advise the Biometrics Branch accordingly. In answer to Mr. Stocker's query regarding the possibility of Branch personnel assisting in the conduct of the study, Mr. Goldberg noted that this might be possible in a jointly conducted study. The Branch is always interested in appropriate research and is anxious to discuss research projects and the means for support of such projects with any interested State.

2. Study of Association of Perinatal Factors with Strabismus in Negro Children

**C. Morton Hawkins, Statistician,
Biometrics Branch, NINDB.**

Mr. Hawkins presented a progress report of a study of the association of perinatal factors with strabismus in Negro children in Baltimore, Md. He noted that a more detailed account of the design could be found in summary and in detail in the Proceedings of the Second Annual Conference.

The conferees were reminded that the study was a retrospective one of Negro children with strabismus who were 13 years of age or under, and matched controls, to investigate possible etiological factors associated with the occurrence

of strabismus in Negro children. The study was being conducted jointly by the Biometrics Branch, NINDB, and the Department of Preventive Medicine of the University of Maryland School of Medicine.

The study had two major objectives: (1) To determine whether the mothers of children with strabismus were different from the mothers of control children in reported prenatal and obstetrical complications and (2) to determine whether the distribution of birth weights of children with strabismus was different from that of children selected as controls. The control group was selected from birth certificates and was matched with cases on the following variables: date of birth, place of birth (that is, the same hospital), sex, and maternal age. All original matched controls that died in the neonatal period were being replaced by appropriately matched neonatal survivors.

When all of the data on cases and controls had been collected, the birth weight distributions of the case and control populations would be compared. In addition, the following variables would be compared for the two groups: (1) Prenatal care, (2) prenatal complications, (3) post-obstetrical history, (4) fetal presentation and position, (5) type of delivery, (6) length of labor, (7) toxemic, hemorrhagic, mechanical, and medical complications of delivery, (8) reported abnormalities of infant, (9) reported length of gestation.

It was planned to include in the study approximately 400 cases and 400 matched controls. Data had been collected on approximately 140 cases and their matched controls. As the protocols were completed, they were being edited and coded. All of the data should be collected by the end of 1964 and it probably would be sometime in 1965 before tabulations are prepared and analyzed.

3. Study of Survivorship and Causes of Death Among the Blind in Massachusetts

Prepared by Eugene Rogot, Statistician, Biometrics Branch, NINDB. Presented by C. Morton Hawkins, Statistician, Biometrics Branch, NINDB.

Mr. Hawkins referred to page 15 of the 1963 MRA Proceedings for a brief review of this study's objectives and basic plan.

The study objectives were—

- (1) To determine survival and sight recovery rates for blind persons by age, sex, and cause of blindness; and
- (2) To determine the distribution of causes of death among blind persons by age, sex, and cause of blindness.

These data will be compared to corresponding rates (and distributions) observed in the general population.

The principal sources of information are records of the Massachusetts Division of the Blind and death certificates from the Massachusetts Vital Statistics Office. The study population consists of all persons first registered blind by the Massachusetts Division of the Blind between January 1, 1940, and December 31, 1959. The closing date for followup was December 31, 1961. The definition of blindness being used is the MRA definition.

The population finally included for study consisted of 11,732 individuals. Of the total study population 5,203 are male and 6,529 are female. Nearly 6,000 or slightly more than half were 65 or older at registration.

The final composition of the study group by major "status" categories was as follows:

Actives (i.e., still blind on the study closing date) -----	5,089
Deaths -----	5,706
Sight restored-----	492
Lost to followup (i.e., moved and unable to locate) -----	445

The proportion lost to followup was about 4 percent. Of the 5,706 deaths, certificates were found and cause of death information abstracted for 5,473 or 96 percent in all. (Of the remaining 233 deaths, 39 were known to have died out of State.)

Mr. Hawkins noted that the analysis had not been completed, so that the few results to be presented and the handouts must be considered preliminary in nature. These results were intended to illustrate the scope of the basic statistical analyses to be done as well as suggest possible new analyses or studies for the future.

One table of the handout presented observed and expected 10-year survival rates, expressed as percents. For each age-sex (or diagnosis) group, the *observed value* represented the proportion of the Study population of blind persons in that age-sex (or diagnosis) group surviving 10 years from registration; the *expected value* was the corresponding estimate for the general population in Massachusetts. (The expected values were derived from the State life tables for white males and white females for 1949-51.)

Mr. Hawkins stated that the table showed that observed survival rates were lower than expected for each age-sex group. Differences were more pronounced at ages under 65 than for ages 65 and over. It was noted that this analysis was also being done by single years of followup.

Also in that table, a number of major affection and major etiology groups were shown. Of these, all except possibly glaucoma had lower observed than expected 10-year survival rates. The most pronounced difference reported was for those with diabetes as the cause of blindness. Again, Mr. Hawkins pointed out that this type of analysis was being done by single years of followup.

In order to investigate causes of death—the second study objective—a sample of the kind of statistical analysis being done was shown in another table. The probabilities of dying from some of the major causes of death were given for 10 years of followup, for females aged 65-74 at registration. It was noted that the excess mortality for this group was largely due to heart disease, diabetes, vascular lesions, and general arteriosclerosis. Accidents and residual causes showed virtually no difference between observed and expected, and cancer, surprisingly, showed lower mortality than expected.

Since the Massachusetts Survivorship Study consistently seemed to indicate poorer survivorship among the blind than among the general population, Mr. Hawkins indicated that it was of particular interest to compare this study's results with those obtained by the Metropolitan Life Insurance Company in their 1923-33 study. Such a comparison was given in a third table in terms of the ratio of observed to expected deaths by age group for the two studies. Only

the first 10 years of followup in the Massachusetts study were considered in order to make a better comparison with the 10-year Metropolitan Life Insurance Company study. It was noted in this table that ratios were lower for the Massachusetts study for the younger ages and for ages 55 and over. For ages 75 and over, there was essentially no difference between observed and expected in the Massachusetts study with ratios nearly equal to unity, while the insurance company study showed ratios of 1.7 and 1.5 for the 75-84 and 85 and over ages. Overall, the observed to expected ratio was 1.45 in the Massachusetts study compared to 2.47 in the Metropolitan Life Insurance Company study.

In concluding Mr. Hawkins added that analyses were also being done with respect to calculating sight recovery rates.

Discussion

In the discussion which followed the presentation, the tentative findings were reviewed and their possible limitations emphasized. Findings were stated as being preliminary in that the study analysis had not yet been completed. Some further comparison with the Metropolitan Life Insurance Company study was made pointing up differences in definitions of blindness used, as well as other differences between the two study populations. There was considerable discussion about diabetes, as well as other conditions and factors, affecting survivorship among the blind.

VI. THE NATIONAL SOCIETY FOR THE PREVENTION OF BLINDNESS STANDARD CLASSIFICATION OF CAUSES OF SEVERE VISION IMPAIRMENT AND BLINDNESS

a. STATUS REPORT

Prepared by Dr. Ralph G. Hurlin, Chairman, Committee on Operational Research, National Society for the Prevention of Blindness.

Presented by Elizabeth M. Hatfield, Consultant in Statistics, National Society for the Prevention of Blindness.

Mrs. Hatfield reported that Dr. Hurlin's Committee (a subcommittee of the Committee on Operational Research, National Society for the Prevention of Blindness) regretted to report that its revision of the coded Index of Diagnostic Terms was still in process.

When the present Index was submitted for use in 1963 the Committee expected that its early use would indicate need for changes and that a revision would be made in time for use at the beginning of 1964. The need for improvement of the Index was indicated and revision undertaken in October 1963 with Dr. Marta Fraenkel, primarily responsible for the work. However, serious illness had prevented Dr. Fraenkel's participation in the revision.

Mrs. Elizabeth Hatfield, Consultant in Statistics, National Society for the Prevention of Blindness, and Mrs. Helen Moorhead, Medical Record Librarian, Biometrics Branch, NINDB, functioning as *de facto* members of the Committee, contributed to the revision through their knowledge of the coding problems and the difficulties faced by the coders in the handling of physicians' eye reports which vary greatly in form and completeness.

The Model Reporting Area States were thanked for their response to the Committee's request for indication of inadequacies of the Index and for suggestions concerning needed changes. Helpful replies were received from most, though not all, of the agencies that used the Index in 1963. Some of the suggested changes had already been made while others depended on decisions to be reached in future committee sessions.

A provisional revision of the 1963 Index was being reviewed by the two ophthalmological members of the Committee, Dr. Richard Hoover and Dr. Ira Jones. A meeting had been scheduled at which it was hoped decisions could be reached on several underlying problems and also on specific coding instructions to be assigned for a considerable number of particular diagnostic terms.

It was pointed out that an Index must have two principal purposes. One is to facilitate the task of the coder. This is especially true in programs such as the Model Reporting Area where the cause of blindness data are collected

and coded in multiple central offices by coders who may lack either much training or experience in interpreting physicians' reports, and who frequently have no opportunity to refer all questions to a supervising authority. Previously it had been believed that the Index could profitably omit many purely descriptive or modifying terms that merely indicated the duration or severity of, or alternative course taken by, a disease without signifying a distinction between distinct entities. It now appears the Index should include many such terms since they are terms which are used in the cause reporting and must be dealt with by the coder.

The other and far more important of the two principal purposes of the Index is to promote uniformity and consistency in the assignment of the diseases found and reported by physicians to the categories of the accepted classification scheme. Without an Index coded specifically to the Classification, much inconsistency of the Classification would occur even if the task were performed by well-trained and experienced coders; and such inconsistency would be totally obscured in the figures resulting from any classification. A virtue of an adequate coded Index if it were followed, is that it would reveal, to those who might be concerned to know, how particular diseases had been treated in the classification procedure.

To satisfy both of the chief purposes, the Index should avoid presenting the coder with "multiple choices." The terms indexed should be listed in such detail that specific code instructions could be given, and less reliance placed on footnote instructions to ascertain the appropriate code within a specified portion of the Classification.

It was hoped that the revised Index would prove to be a more useful instrument than that Index now in use.

b. REPORTING AND CODING CAUSES OF SEVERE VISION IMPAIRMENT AND BLINDNESS

1. Problems and Consideration of Data Quality

Elizabeth M. Hatfield, Consultant in Statistics, National Society for the Prevention of Blindness.

Mrs. Hatfield conveyed greetings to the conferees from Dr. John W. Ferree, Executive Director, and Mrs. Virginia S. Boyce, Assistant Executive Director, National Society for the Prevention of Blindness (NSPB).

She pointed out that one of the primary objectives of the MRA is the production of comparable or poolable data on blindness in each of the member States. Because of their need for reliable data on the causes of blindness in order to plan sound programs for prevention, the development of good cause data is a major concern of the NSPB. To this end the Society's attention and assistance in the MRA program has been directed to the development of standardized procedures for the collection and classification of medical information on the causes of severe vision impairment and blindness.

Members of the National Society's Advisory Committee on Operational Research (Dr. Ralph G. Hurlin, Dr. Marta Fraenkel, and the ophthalmologist members Dr. Richard E. Hoover and Dr. Ira Jones) have been primarily responsible for the work on the Standard Classification of Causes of Severe Vision Impairment and Blindness, the Index of Diagnostic Terms, and the suggested standard Physician's Report of Eye Examination.

In addition the National Society has contributed, through Mrs. Hatfield's services, to the initial planning for the MRA and, more specifically, training and advice on coding causes of blindness. Mrs. Hatfield expressed her regret that due to staff and time limitations she had not been able to devote more time to individual assistance and instruction.

Consultative services and training are an essential part of the program for the development of good cause data. In recognition of this the Biometrics Branch added to its staff a well-qualified medical record librarian who had spent a great deal of time studying and working with Mrs. Hatfield on proper coding procedures, and in assisting the NSPB on the Index of Diagnostic Terms and Manual of Instructions. She and Mrs. Hatfield will continue to work closely together on coding problems and the development of educational materials to assist in this program.

The Workshop on Coding Causes of Blindness in November 1962 provided an opportunity to present the Standard Classification and the Index of Diagnostic Terms to the consultant ophthalmologists and persons responsible for the coding. At that Workshop explanation was given of how the Index should be used to tie together the diagnosis, as reported by the examining ophthalmologist, and the Standard Classification. Unfortunately a manual of instructions was not prepared nor was there sufficient time for adequate instruction for the coders.

In order to evaluate the quality of the coding being done and to provide assistance with problems, it was suggested at the Workshop that a sample of the new case reports be submitted each month for review. Participation in this program was disappointing. Four States submitted records more or less routinely and three others on one occasion only.

The opportunity to review some 1,000 records was extremely valuable. It not only permitted checking the coding but demonstrated the need for: changes in the Index and Classification; additional training and instruction of coders; further clarification of the classification principles with the consultant ophthalmologist; specific classification rules and instructions; and education of the examining ophthalmologist concerning the program and reporting of medical diagnosis for classification purposes.

As a result of the review of these records several problem areas or sources of error were observed. Some of these had been enumerated at the last Annual Conference but were important enough to bear repeating.

First, there were errors arising from the use of the Index and Standard Classification. The Index was provided to assist the consultant ophthalmologists and coders in assigning the proper classification codes. It was intended to serve as a bridge between the diagnosis as reported by the examining ophthalmologist and the Classification, and was to be used rather than the Classification in coding the causes of blindness. The Classification simply provided an abbreviated summary in useful groupings of all possible diagnoses which might be reported. For a clarification of the exact inclusions in a particular

category reference must be made to the Index. Perhaps at some future date a listing might be provided of all inclusions (diagnostic terms) under each specific category of the Index.

Mrs. Hatfield emphasized that the importance of consistent use of the Index by all could not be overstressed if there was to be comparable data on cause. All coding must be done in accordance with the Index. No changes in coding assignment or additions should be made without prior clearance through the Biometrics Branch.

Errors arose through failure to use the Index as intended. Decisions had been made and codes assigned which were not in agreement with the accepted standard. It was most important that the consultant ophthalmologist and the coder become thoroughly familiar with the Index and proficient in its use. The beginning coder should not rely on his memory. Reference should be made to the Index to ascertain the proper code in each instance, acceptable etiologies corresponding to a particular ocular affection, and preferences where more than one assignment is possible.

Some of the code assignments in the Index are admittedly arbitrary but necessitated by lack of agreement among ophthalmologists or by certain basic priorities set up for classification. In the review of reports and study of the Index it was found that certain changes are indicated. These are being included in the revised Index.

Second, a major source of coding problems was in the interpretation of records. Many errors had resulted from an incorrect interpretation of the reported diagnostic information. This led to a cause assignment, when a choice had to be made, to a secondary condition, end result, or sequela of the condition responsible for impaired vision rather than the condition itself; the less serious of two or more conditions; eye conditions and etiologies which did not go together; the cause for the first rather than last eye to go blind, where diagnoses differed in each eye.

The lay coder should not be expected to interpret medical diagnoses for adequacy and consistency or to make decisions concerning the probable cause of blindness. Reports requiring interpretation should be referred to the con-

sultant ophthalmologist for review. He should pass on for followup those which require additional information for classification. It was hoped that the consultant ophthalmologist would have sufficient time and interest also to review all or at least a sample of the cause coding. It is felt that the coding of causes of blindness should be the responsibility of the consultant ophthalmologist and that the coder would be the one designated to do the work under his supervision.

The problem of interpretation pointed up the need also for more training and consultation services for the coders, specific coding rules, and continual review of the coding.

The report form in use very definitely contributed to interpretation problems. If the section on diagnosis was not geared specifically to the Classification, then reporting of medical information might be inadequate or incomplete. If the request for diagnostic information was not specific enough, the examiner might report just what he desired. For example, he has not, frequently because he was not asked to, differentiated between the "primary" and "secondary" eye affection, or he has confused the ocular affection and the etiology or underlying cause of the affection.

Mrs. Hatfield felt that the standard report form would do much to clarify the situation, but it would not in itself necessarily produce desired results automatically. The ophthalmologist would have to be oriented to the problems and requirements for good cause data. This was evident from completed reports, on the recommended form, which had been reviewed.

It was obvious that some ophthalmologists did not take the time to study the form or did not clearly understand it. Many apparently turned over the report form to the office secretary for completion from their examination record without further instructions. She cannot be expected to interpret the record in terms of the desired report of cause of blindness. This must be the responsibility of the ophthalmologist.

Prior experience of the coders or States with the Standard Classification has been another source of coding errors. Persons who have coded causes of blindness under previous edi-

tions of the Classification have had a tendency to follow old procedures and code automatically from the Classification rather than on the basis of the Index.

In some instances it was observed that in recoding previously coded register cases, old code numbers were changed to what were judged to be numbers of corresponding categories in the revised Classification. This could not be done automatically without reference to the Index because some of the old concepts regarding etiologies had been changed, the Classification had been expanded, and inclusions were not comparable in all categories. Comparability charts would have to be carefully worked out for automatic recoding.

Since the program of routinely producing statistics on severe vision impairment and blindness has been well launched, serious attention should be given to improvement in the quality of the data, most especially that on cause. Mrs. Hatfield noted that there were many limitations in the data being produced which would have to be taken into consideration when the data for the first few years of the program were used. Further refinements were needed and were now being made and definite rules would have to be set up. This has been the first experience in coding causes of blindness on a large scale. The experience and qualifications of the coders vary. All of the coders have had a year in which to become familiar with the reporting of medical diagnoses, with the terminology, and with the Classification and Index. Therefore, the future should show progress. With a further gain in experience, techniques and procedures could be improved.

A concerted effort must be made by all to improve the quality of the data on cause. It must be continuous and unceasing. It must be directed toward improving the quality of the data from two angles: *reporting* and *coding*.

Mrs. Hatfield indicated there were several ways in which the quality of the reporting could be improved.

First and foremost would be the adoption of a standard report form. The importance of the report form, particularly of the section on diagnosis, could not be overemphasized. If all medical eye specialists were asked to report diag-

nostic information in the same way, this would do much to help achieve comparable data on cause. The recommended form called for the reporting, in a logical manner, of information necessary to accurately classify the cause of vision impairment according to the Standard Classification. If diagnostic information were properly reported, interpretation problems would be at a minimum.

Reporting of *all* legally blind persons to the agency maintaining the register should be on the standard form. If it were not, then every effort should be made to secure another report, signed by the examining ophthalmologist, on the prescribed form. It might be necessary to work with hospitals and clinics, and even private physicians, in setting up an appropriate record form so that diagnostic information would be recorded in the same manner in which it was to be reported. This would facilitate completion of the report by the office secretary or a medical social worker from the record. The report should, in any case, be signed by the ophthalmologist, for he is the person certifying to the cause of blindness.

Also, all agencies within the State which provide services to blind persons should be encouraged to use the standard form. This would facilitate the interchange of information.

The National Society has developed a modification of the standard physician's form to meet the special needs of educators. In all essential aspects it is exactly the same as the standard form. The form, "Eye Report for Children with Visual Problems," had been widely distributed to residential schools for the blind, education specialists in State departments of education, some special teachers, and consultant ophthalmologists, persons responsible for vision screening or child health in the State departments of health, and superintendents of parochial schools. It had been well received and many schools had decided to adopt it. The use of this form in the schools will be helpful to the entire program.

While a standard report form in itself will not insure adequate reporting of diagnostic information, it would provide a uniform manner of reporting. The reliability of cause-of-blindness data is dependent upon the cooperation of

informed and interested ophthalmologists. An educational campaign must be launched to acquaint them first of all with the MRA program and then to instruct them in the proper method of reporting medical information on the cause of blindness. It must be the responsibility of the examining ophthalmologist to designate the cause of blindness. He is in the best position to do so. Neither the consultant ophthalmologist nor the coder should be required to determine from the information reported what the cause of blindness might be. Hopefully, the informed ophthalmologist who understood the need for complete information and the requirements for the purpose of classifying the cause of blindness, would be stimulated to cooperate and report to the best of his ability.

The States' consultant ophthalmologists should be helpful in carrying on this program through personal contacts with their colleagues, and the State and local medical and/or ophthalmological societies. Ways will be explored in which this problem can be brought to the attention of all ophthalmologists through national organizations and schools of medicine. To assist in getting the message across an effort will be made to produce some educational pieces. Eventually it was hoped to have an instruction pamphlet for ophthalmologists. For the interim it was planned to prepare a brief statement defining the cause of blindness for MRA purposes and an explanation of correct reporting of diagnostic information with examples which would be useful for this purpose. Development of a good working relationship with all of the medical eye specialists would be of great help in improving not only the quality of reporting but the completeness of reporting in general.

An integral part of the educational campaign is the *query program*. This is an ongoing program to obtain additional information or clarification whenever necessary to accurately classify the cause of blindness or to complete the report. Such a program is essential if the medical eye specialists are to be informed concerning the data required for classification purposes and if data on causes of blindness are to be improved. Contacting these specialists for additional information would be most effective if it were part of the overall plan to acquaint them with

the MRA program and to keep them aware of its progress.

Medical diagnoses are reported with varying degrees of completeness and adequacy. Through a routine query program inadequate reports are brought to the attention of the examiners and at the same time they are informed regarding proper reporting. If this were not done the examiner would have no way of knowing that they were unacceptable. Unless there were insistence on better reporting, the examiner would continue to do an unsatisfactory job of reporting. He must also be convinced that the entire completed report is serving a useful purpose.

The second facet of improving data on cause requires consideration of ways in which the quality of the coding can be improved and maintained at a high level.

The quality of cause-of-blindness data is largely dependent on the reporting. If reporting were generally incomplete, then a high proportion of the cases would fall into the "no report" categories, for example. This would serve to minimize the importance of reported causes.

Regardless of the quality of the reporting it is essential to achieve and maintain a high degree of accuracy in the coding. Some might question the value of a concern with accurate coding if the reports are inadequate. If both reporting and coding are poor any meaningful interpretation or comparison of the data would be impossible. Standardized procedures should be followed and used consistently and uniformly from State to State. If this were done with a high degree of reliability, then at least one variable would be eliminated and it would be known with some certainty that the quality of the data was dependent almost entirely upon the source—the examining ophthalmologist. Hopefully, it will be possible to improve reporting as time goes by. This will be difficult because of the large number of examiners involved. In comparison, improving and maintaining the quality of coding should be relatively simple if the sources of error could be eliminated or minimized.

First, the Index of Diagnostic Terms is being revised. Every effort is being made to produce an Index which would be sufficiently detailed to

be of maximum use to the coder, which would be free of ambiguities, and in which coding assignments were consistent with the best ophthalmological thinking. This has not been an easy task but when completed it is anticipated that the coders will find the revised Index an extremely useful tool.

An endeavor will also be made to set up rules and guides to assist the coder and consultant ophthalmologist in interpreting and making decisions regarding complicated reports. There will no doubt be situations not covered by the rules. These must be reported through the Biometrics Branch. There will also be instances in which additions to the Index might be required.

To be sure that the cause data produced by each State are indeed comparable, a *quality control program* is a must at this stage. This program would involve a review in the Biometrics Branch of the coding being done in each individual State. Without an evaluation of the actual code assignments, there could not be any certainty that the tools and prescribed procedures were being used uniformly and with equal reliability by all coders and, thus, that the data on cause from each State were entirely comparable and poolable.

Through a quality control program it would be possible to: (1) Evaluate the quality and comparability of the coding; (2) evaluate the adequacy of the diagnostic reports; (3) determine problems encountered in coding; (4) determine the need for additional rules and special instructions.

The review of more than 1,000 records this past year revealed an error rate which varied from 25 to 50 percent. In contrast, Mrs. Hatfield noted that in the national vital statistics program only a 2-percent error is acceptable in coding causes of death! As a part of that program, coding done by the States is checked on a sample basis. Whenever the error of a particular State exceeds the 2-percent limit, coding of all deaths is checked until such time as an acceptable error rate again prevails.

A check of the coding provides an opportunity for continuous training of the coders and reorientation of the consultant ophthalmologists.

Mrs. Hatfield noted that data on causes of severe vision impairment and blindness could be expected to vary from State to State. These variations were due to a number of factors. Differences in the composition of the population would result in different distributions by cause. In a State where the population was comparatively young, for example, there would be causes common in children and young adults and the rate of blindness could also be expected to be lower. On the other hand, a State with a greater proportion of persons in the older age groups could be expected to have a higher rate of blindness and causes associated with the aging process such as glaucoma, cataract, diabetes, vascular diseases, and senile degeneration. Differences in the racial composition of the population could also be expected to contribute to the variations in the rate of blindness and might also affect cause distributions, but data by race were insufficient to determine whether or not any real cause difference existed.

Completeness of registration is another factor which will affect the data on causes of blindness. The distribution of causes would be different if children were not adequately reported to the blindness agency, or if older people were not reported because they were receiving old-age assistance rather than aid-to-the-blind.

Errors in coding also contribute to differences in distributions by cause if they are consistent and occur frequently enough. These would be difficult or impossible to determine without some control over the quality of the coding. Decisions could be made in coding, for example, which were not in accordance with the Index and accepted procedures. In classifying the causes of blindness it is attempted, insofar as possible, to assign to the cause which *initiated* the series of events leading to serious vision impairment and blindness. Secondary conditions should not be coded. However, if in a particular State, for reported cases of "secondary glaucoma" which could follow any number of stated conditions, preference were given to the secondary glaucoma, then the glaucoma count would be inflated and not comparable with that from other States. Likewise, if assumptions were made by some States and not others concerning the etiology of a condition when it was

not reported, such as the assignment of all glaucoma or cataract cases to "unknown to science" unless otherwise specified, this would throw the cause data off. Because such conditions exist, it is difficult to evaluate the cause tabulations submitted by each State; it is not possible to be certain that they are entirely comparable. If the quality of the coding were completely under control, then other factors could be examined for an explanation of the differences which exist between States, but the coding factor cannot now be eliminated.

Mrs. Hatfield reemphasized that there is no room for individual differences, preferences, or interpretations incompatible with the classification scheme if there is to be truly comparable data on cause. Efforts have been exerted to make the tools and procedures as professionally sound as possible. Even though all may not agree entirely with what has been done, adherence to this concept is essential if tabulations from each State are to be pooled for producing national estimates.

Mrs. Hatfield pointed out that the ideal situation would be for all coding of causes of blindness to be done in a central office. Since this was not feasible, a review of an adequate cross-section of the coding done in each State seemed to offer the most efficient control.

The quality control program would be of value not only to the NINDB but to each individual State. It would be a continuing way of improving the quality of the coding, stimulating the interest of the consultant ophthalmologists and the coders, and exchanging information regarding problems.

With the addition of Helen B. Moorhead, Medical Record Librarian, to the staff of the Biometrics Branch an efficient full-scale program can now be conducted. To be effective there must be 100 percent participation by the members of the MRA.

Mrs. Hatfield mentioned that Mrs. Moorhead would discuss in her presentation specific proposals for the query program and the quality control program.

Mrs. Hatfield felt that the librarian could provide the consultative services and assistance necessary to keep the MRA program moving. She and Mrs. Hatfield would be working close-

ly on the development of materials to assist the member States and in providing advice on coding problems. Training would be provided to new coders. Consideration would also be given to another coding workshop at some future date.

Mrs. Hatfield stated that Model Reporting Area members should be proud of the fact that one year of data on cause, in spite of its limitations, was now available from nine States. She considered this a milestone and felt that the future would bring continuing progress.

2. Specific Proposals for Improving Quality

Helen B. Moorhead, Medical Record Librarian, Biometrics Branch, National Institute of Neurological Diseases and Blindness.

Mrs. Moorhead expressed her satisfaction in being associated with the Model Reporting Area. As a hospital medical record librarian she had been involved in the classifying and coding of diseases and looked forward to assisting the MRA with this interesting and, at times, perplexing activity.

Mrs. Moorhead described some of the services she was providing to States in connection with the MRA program. Among the States preparing for membership in the Model Reporting Area were New Mexico and South Dakota. Mrs. Moorhead had visited each of these States to train the personnel who were to do the cause-of-blindness coding and was gratified to see that this important work was in the hands of interested and conscientious individuals. In both of these States the coders had previously abstracted considerable information from the records for items of the register other than the causes of blindness. This was a definite asset, as they were familiar with the reports and the case folders and had acquired some vocabulary in ophthalmologic conditions. Training included orientation on the Standard Classification of Causes of Severe Vision Impairment and Blindness. The diagram of the eye which is published by the National Society for the Prevention of Blindness was used to locate the anatomical sites of some of the diseases the coder would encounter.

A considerable portion of time was given to acquiring familiarity with the use of the Index by coding practice. This was scaled for increasing degrees of difficulty. Items were selected for practice which were known to have been a problem based on Mrs. Hatfield's experience with actual reports. The remainder of the time was used for coding of the States' own records, an experience which Mrs. Moorhead found valuable for herself as well as for the trainee. Personal instruction was supplemented by review of coding as the work on the register progressed in these States. They mailed photocopies of the actual eye reports (names omitted), with their codes written in, to NINDB. These were reviewed, corrections made where necessary, and returned to the States with an explanation for any change in code.

In addition to providing such services mentioned above, Mrs. Moorhead advised the conferees that the member States were urged to write NINDB on any questions they have. She noted that answers might not always be immediately available, but every effort would be made to find satisfactory solutions to problems.

In time a newsletter will be circulated for all the membership. This would be an addition to the training program, and would serve as a forum for discussion of classification rules. Between annual conferences it could serve as a medium of communication, and a means of keeping the Index current by circulating changes or additions.

Mrs. Moorhead mentioned that some of the members had inquired about the best way to establish a query program for obtaining additional data from examining physicians who had submitted incomplete or ambiguous reports. Since the Model Reporting Area was the first effort to obtain extensive and accurate data on a large scale directly from reports of specialists in afflictions of the eye, it presented a unique opportunity to obtain improved reporting from them. As the specialist became familiar with what was needed, the no-report category in the data should shrink.

Mrs. Moorhead pointed out that there are problems in classification which stem from the method of reporting and can be resolved only by the examining physicians. For instance, the

meaning of "primary affection" is not the same to all doctors. Some interpret it as the major condition seen at the time of examination. Not infrequently, this is an end result or complication of the underlying affection which is actually the basic cause of blindness. An instance of this is the reporting of a primary diagnosis of "enucleation." This information has its place, but, of course, it gives no clue as to what the primary condition is in terms of the disease or injury which started the chain of events that led to the removal of the eye.

Etiology is omitted at times. Cataracts are frequently reported with no mention of the cause. Because of the patient's age, it is suspected they could properly be classified as senile degeneration, but only the examining doctor can turn this suspicion into certainty.

Another problem occurs where each eye is blind from a different cause. Physicians do not report which eye was the last to be severely impaired, so the coder does not know which affection should be classified as the cause of blindness.

Adoption of or incorporation into State report forms of the Standard Eye Report developed by the National Society for the Prevention of Blindness would help to obtain reporting in the manner best suited for classification of causes of blindness. However, this is not the entire answer. A query program should be developed to interpret reporting needs to the medical specialists. It was suggested that such a program have four steps:

- (1) Before starting a query program send a letter to each ophthalmologist and eye-ear-nose-and-throat specialist, describing the objectives of the MRA program and announcing the State's participation in it. Inform them that this is an effort to obtain extensive and accurate data on blind persons and on the causes of severe vision impairment and blindness from specialists in afflictions of the eye. Solicit their cooperation in providing complete information on visual acuity measurements, onset of blindness, history, and the site and type of eye conditions and their etiologies. Copies of the MRA Brochure are available for inclusion with

such letters. Many States have already accomplished this first step.

- (2) Review reports as soon as they are received and submit those which seem to have inadequate information to the consulting or supervising ophthalmologist for his recommendation as to whether or not the physician should be queried for additional data. Where it can be arranged, querying by the consulting ophthalmologist is recommended. Where this is not possible, it should be done under his guidance. Persons who gain *thorough* familiarity with ophthalmologic terminology and disease processes will be able to operate the query program with only occasional assistance from the consulting ophthalmologist.
- (3) Follow-up letters requesting additional information should be sent immediately. Special form letters should be devised for this phase.
- (4) The last, but an important part, would be to feed information back to the doctors so that they will know that the data they report are utilized. This will also provide an opportunity for reminding the doctors of the necessity for reporting all patients whose vision is severely impaired.

It is planned to devise letters and forms for two of these steps which each member State can easily adapt to its own use, if it so desires. These should also be helpful to new States joining the program. One would be a letter informing the doctors of the State's participation in the program. Mrs. Moorhead said that she was very much interested in North Carolina's report on what the supervising ophthalmologist did when North Carolina adopted a new report form, and was of the opinion that many conferees would feel that initial contacting of the doctors can be done more effectively by the State supervisory ophthalmologist. It might be most effective if the emphasis is on what is being done in the State rather than on the cooperative project with other States. NINDB would like to learn the ideas and opinions of the members on these points.

There is a particular need to develop forms for securing additional data from the physicians. These should be effective in getting precisely the desired information and also economical of the time of both the physician and the agency staff. Mrs. Moorhead asked that any members who were contacting their examiners for additional data report their experience and suggestions to NINDB.

When forms are developed, before they are distributed generally, it would be advantageous if one of the members would test them in actual use so that their effectiveness could be evaluated and needed improvements made.

For the final step of a query program, that of feedback to the doctors, the Biometrics Branch can furnish copies of the annual statistical reports. However, the physicians would probably take particular interest in reports States would prepare from their register cards, showing such items as additions, removals, and services by county. Many are doing this. Again, NINDB would appreciate receiving copies of all members' reports.

In addition to improving reporting, extension of effort in another area is needed. Mrs. Moorhead observed that Mrs. Hatfield had already set forth the purposes of a quality control program. It has always been known in theory, and from the experience of national vital statistics activities that such a program would be desirable. Examination of the statistics on causes of blindness for 1963 makes it evident that uniformity has not been obtained. It must be achieved if the Model Reporting Area is to make the contribution to accurate information on cause of blindness which is the desire and objective of each member.

A case in point is cataracts. Nearly 18 percent, or more than one case in six, was coded to an unknown-to-science etiology. The only code in the Index for cataract with an etiology of unknown to science is the one for cataract in myotonic dystrophy. Everyone would readily agree that, in any State, not every sixth client who has cataracts would also have myotonic dystrophy. A quality control program would show where these cases belong.

Another tendency seen with cataract is to code these as senile in aging people when the

physician gives no information on the etiology. This undoubtedly is an assumption that would be verified as right in a number of cases if additional information were available, but without this information the data show so many cases of *possible* senile cataract rather than so many cases of *positive* senile cataract documented by medical authority. Many people are coding cataracts of this type to "no report on etiology," which is felt to be the proper classification if the data are to be valid. A quality control program would determine quickly when data are being produced that cannot be pooled and compared because of differences in the interpretation or application of coding principles.

Mrs. Moorhead presented the following proposal for a quality control program:

For patients examined by an ophthalmologist or eye-ear-nose-and-throat specialist, that each member forward to NINDB monthly exact copies of the eye examination report for all new cases entering the register, if this amounted to 400 or less per year. Where there were more than 400, a plan would be worked out for sampling the register which would provide a minimum of 400 records per year. The code assigned for the cause of blindness should be entered on each report forwarded.

If it became necessary at any time to train new coders for the current register, it would be advisable to check all of the coding until facility with classification was acquired, and then revert to the regular sampling procedure.

Copies of a query form or any additional information pertaining to the medical diagnosis, the history, or onset which would influence the assignment of a code should also be attached. For those qualifying as legally blind through a limitation in visual fields, the field charts should be included, unless this information was recorded elsewhere on the report. Those who hesitate to send out copies of records bearing the names of clients could obliterate the name and substitute the register number for identification purposes. Care should be taken not to obliterate also the age and other pertinent information. Mrs. Moorhead assured the members that all reports would be safeguarded and treated in accordance with the ethics of protecting medical records.

She asked each State to consider whether it could be fitted into the office schedule to mail these records by the 15th of every month. It would be necessary for NINDB to organize this work and allot sufficient time for quite considerable effort that would go into verifying and commenting on the reports. With reports submitted on a regular schedule, a summary report of performance and the comments on recommended changes in the codes would be returned to the States within 60 days.

As the quality control program progressed, it was anticipated that it would be necessary to verify only a sample of reports from States with a very low error rate, and to resume complete verification only if the error rate were found to be increasing.

The exact copies could be prepared in the way that was most convenient. Photocopying would be preferable, as it would give excellent legibility and eliminate any possibility of transcription errors. However, where this was not possible, other methods of legible reproduction or hand or typewritten transcripts would be satisfactory.

Mrs. Moorhead inquired if the cost of the program could be absorbed and asked that all States which would find cost an obstacle, let NINDB know whether they would reproduce the copies in their own offices or have them done commercially and what the cost would be per copy.

In conclusion Mrs. Moorhead said that, in this pioneer program to provide accurate data on causes of blindness, NINDB is interested in sharing the members' experiences and hopes to furnish them with a training and quality control program that will be a continuing stimulation to the key people, the registrars or coders, and will provide a constant examination of what is needed to help them in this important task.

Discussion

Mr. Stocker of Oregon asked if acknowledgement would be made of reports submitted and was assured that this would be done.

Mr. Meyer raised the question of whether any test had ever been done to see if different States make uniform interpretations when coding from the same system. Dr. Goldstein observed that

this had been done in other fields but knew of no such research in the field of vision impairment.

It was pointed out by Mr. Goldberg that there will be variations in completeness of reporting from different specialists, but the best ophthalmological information available must be classified in a uniform manner by all member States in order that the objectives of the Model Reporting Area may be met.

Dr. Goldstein asked if any States had objections to participation in a quality control program, and there were none voiced from either member or nonmember States.

VII. SPECIAL PROBLEMS RELATING TO EYE REPORTS

Irving D. Goldberg, Assistant Chief, Biometrics Branch, NINDB.

a. Updating Eye Examination Reports

Mr. Goldberg brought to the attention of the conferees a special problem relating the coding of discipline of examiner and cause of blindness when information on eye examinations is brought up to date. He noted that this problem related to multiple eye reports; and it came to particular light in the course of assisting States in the development of their registers when these multiple eye reports had to be reviewed for coding at the same time. This problem also exists after the register is established, and it was thought that the nature of the problem was sufficiently important to raise at the Conference. Consequently, a proposal was prepared by the Biometrics Branch which was thought to be administratively simple. This proposal was being submitted at this time to the member States for their approval.

The items of information involved in the proposal are as follows: discipline of examiner, cause of blindness (affection and etiology), date of eye examination, and degree of vision. The problem in coding this information arises when an eye report from an ophthalmologist or an EENT specialist is followed on some future date by an eye report from some other discipline of examiner. Mr. Goldberg emphasized that the aim of the proposal was to keep it administratively feasible and to avoid losing valuable information on cause of blindness, since cause

of blindness tabulations are prepared only for those registrants examined by ophthalmologists or EENT specialists. The proposal follows.

For the purposes of the Model Reporting Area, the item "discipline of examiner" is related principally to information on cause of blindness. It refers to the person responsible for the most recent eye examination report on file with one exception. This exception arises where cause of blindness for a registrant had been reported by an ophthalmologist or an EENT specialist, but a subsequent report has been received from a member of another discipline (i.e., optometrist, general practitioner, etc.) *without any change having intervened which would invalidate the diagnosis* on the earlier report. In this case, cause of blindness is classified from the ophthalmologist's or EENT specialist's report and discipline is coded to ophthalmologist or EENT.

Examples:

1. An ophthalmologist reports a blind registrant to have senile cataract. Later report from an optometrist shows decreased vision. However, it is apparent from the available information that the cause of the registrant's eye condition has not changed. Therefore:
 - a. Cause of blindness remains the same and is coded from the ophthalmologist's report.
 - b. Discipline of examiner remains the same as originally coded (i.e., ophthalmologist).
 - c. Date of eye examination is updated (i.e., date of optometrist's examination).
 - d. Degree of vision is updated (i.e., as reported by the optometrist).
2. An ophthalmologist reports a blind registrant to have senile cataract. Surgery is later performed with vision improvement to better than 20/200, and the person is removed from the MRA register. At a later date, a report from an optometrist again shows corrected vision of less than 20/200. The person is re-added to the register. Here, the original diagnosis of cataract may no longer apply due to the

intervention of the surgery. Thus, all vision information is updated as follows:

- a. Cause of blindness is considered as not reported for MRA purposes.
- b. Discipline of examiner is coded to optometrist.
- c. Date of eye examination is that of the optometrist's.
- d. Degree of vision is that reported by the optometrist.

Mr. Goldberg asked for comments on and approval of the above proposal.

Discussion

Mr. Gambaro inquired as to whether it was necessary to obtain an eye report from an ophthalmologist after receipt of an eye report by an optometrist in order to get cause of blindness information. Mr. Goldberg stated that this would not normally be required although it would be desirable. However, it would have to be a State policy since the MRA could only recommend but could not pay for nor request ophthalmological examination.

In answer to questions by Mrs. Daly and Mr. Gaines, Mr. Goldberg stated that the degree of vision is always updated because the visual status of all persons on the register should be as current as possible regardless of the discipline of examiner. The aim is to have the register provide, insofar as possible, the current status of the registrants for all required information. In particular, Mrs. Daly asked about the handling of constantly fluctuating degree of vision such as that which may occur among diabetics. Mr. Goldberg stated that this was a difficult problem and he suggested that the State use the advice of its consulting ophthalmologist as a guide in the handling of such cases. Thus, if a patient's vision changes frequently the consulting ophthalmologist may determine if this frequency is sufficient to warrant that the person continue to remain on the register as blind.

The conferees agreed to adopt the proposal presented by Mr. Goldberg.

b. Definition of Blindness—Field of Vision

A second problem raised by Mr. Goldberg dealt with that portion of the definition of

blindness relating to field of vision, namely "visual acuity of more than 20/200 if the widest diameter of the field of vision subtends an angle no greater than 20 degrees." The question concerned itself with the interpretation of what constitutes a 20-degree limitation. Apparently, there is a difference of opinion on this matter, including the involvement of the point of fixation.

Mr. Goldberg referred to instructions prepared by the Social Security Board in 1940 directed to State agencies participating in the study of causes of blindness among recipients of aid to the blind. With regard to the category of vision "better than 20/200 with peripheral limitation indicated," the following explanation was given in the Social Security Board's instructions: "To judge the size of the peripheral field remaining one must find the diameter in degrees across the widest portion of the visual field and note its measurement. The limits of a useful field may be symmetrical (i.e., both extremities of the widest diameter may reach an equal distance) or they may be irregular."

Mr. Goldberg noted that this matter was discussed with Mrs. Hatfield who referred the question to Dr. Richard Hoover and Dr. Ira Jones who are consultants to the National Society for the Prevention of Blindness. An effort is being made to attempt to resolve this issue. Mr. Goldberg asked that each of the States obtain from their consulting ophthalmologists opinions as to their interpretation of the 20-degree field limitation specified in the MRA definition.

Discussion

Mr. Gambaro stated that the definition does not necessarily tell how much useful vision remains and he noted that the angle might be wide while the total area of vision is small. He suggested that the MRA look into the standards issued by the American Medical Association and other such sources. Mr. Goldberg stated that the Biometrics Branch is looking into the whole question with the assistance of the NSPB.

Miss Cole wondered if the Branch would look into the matter where vision was confined to one side (hemianopsia). Mr. Goldberg indicated that this was one of the first questions

raised which brought the issue to its present state of exploration. He indicated that the entire question of degree of vision is being reviewed. He had hoped that the definition could be meaningfully and specifically described.

Mrs. Hatfield strongly urged each State to consider Mr. Goldberg's request to have its consultant ophthalmologist provide his interpretation of the field of vision limitation. All of the representatives present agreed to discuss this matter with their consulting ophthalmologists and provide their respective opinions on the matter to the Biometrics Branch.

VIII. MODEL REPORTING AREA TABULATIONS — PROGRESS, PLANS AND FEEDBACK

a. REPORT OF PRELIMINARY TABULATIONS FOR 1963

C. Morton Hawkins, Statistician, Biometrics Branch, NINDB.

(NOTE.—Due to the preliminary nature of the tabulations presented and discussed at the Conference, and to avoid subsequent confusion, the summary and discussion of the presentation by Mr. Hawkins which follow are limited to the general aspects and implications of the 1963 preliminary tabulations. However, a final detailed report of the 1963 tabulations of the Model Reporting Area for Blindness Statistics will be published as a separate document.)

In his opening remarks, Mr. Hawkins stressed that this was a preliminary report of 26 tables prepared solely for discussion at the Third Annual MRA Conference. He reported that the preliminary tables would be revised accordingly upon examination of the punchcards submitted to the Biometrics Branch by the MRA States. He further indicated that the rates presented in the report were subject to change as further population estimates by the Census Bureau are released and improved estimates of the Model Reporting Area population can be prepared.

It was pointed out that data on register additions were probably more accurate than data on register removals and register totals as of December 31, 1963 (that is, prevalence figures), because several States were continuing major revisions and clearances of their registers. Therefore, data presented in the prevalence ta-

bles might reflect biases of such revisions and clearances.

Mr. Hawkins emphasized that the Model Reporting Area, as composed in 1963, could not be considered to adequately represent the United States as a whole. Projecting Model Reporting Area data directly to the United States was discouraged. The presentation was focused on the highlights of the tables. Among the limitations of the data were the relatively high proportion of individuals in some States for whom information was unknown on such items as race, discipline of examiner, etiology, etc. Mr. Hawkins stated that this was one of the areas which the States involved should strive to improve in order to give greater meaning to the data. Also, certain discrepancies between States regarding the interpretation of the coding of the causes of blindness were pointed out as one of the problems to be overcome in the future.

The conferees were reminded that the tables concerned with causes of blindness pertained only to those first additions to the register during 1963 who had been examined by ophthalmologists or eye-ear-nose-and-throat specialists.

The titles of the tables presented and discussed were as follows:

1. Summary table of first additions, readoptions, removals, and end-of-year total on register: each MRA State and MRA total, 1963.
2. All additions to register by age and sex: MRA total, 1963. (Number and rate.)
3. All additions to register by sex and race: each MRA State and MRA total, 1963. (Number and rate.)
4. All additions to register by age: each MRA State and MRA total, 1963. (Number and rate.)
5. All additions to register by degree of vision: each MRA State and MRA total, 1963. (Number and percent.)
6. All additions to register by sex, race, and degree of vision: MRA total, 1963. (Number and percent.)
7. All additions to register by age and degree of vision: MRA total, 1963. (Number and percent.)
8. First additions to register by major affection groups: each MRA State and MRA total, 1963. (Number and percent.)
9. First additions to register by sex, race, and major affection groups: MRA total, 1963. (Number and percent.)

10. First additions to register by age and major affection groups: MRA total, 1963. (Number and percent.)
11. First additions to register by degree of vision and major affection groups: MRA total, 1963. (Number and percent.)
12. First additions to register by major etiology groups: each MRA State and MRA total, 1963. (Number and percent.)
13. First additions to register by sex, race and major etiology groups: MRA total, 1963. (Number and percent.)
14. First additions to register by age and major etiology groups: MRA total, 1963. (Number and percent.)
15. First additions to register by degree of vision and major etiology groups: MRA total, 1963. (Number and percent.)
16. First additions to register by major affection groups and major etiology groups: MRA total, 1963. (Number and percent.)
17. First additions to register by age at loss of sight: each MRA State and MRA total, 1963. (Number and percent.)
18. First additions by discipline of examiner: each MRA State and MRA total, 1963. (Number and percent.)
19. First additions to register by degree of vision and discipline of examiner: MRA total, 1963 (Number and percent.)
20. Total on register by age and sex: MRA total, as of December 31, 1963. (Number and rate.)
21. Total on register by sex and race: each MRA State and MRA total, as of December 31, 1963. (Number and rate.)
22. Total on register by age: each MRA State and MRA total, as of December 31, 1963. (Number and rate.)
23. Total on register by degree of vision: each MRA State and MRA total, as of December 31, 1963. (Number and percent.)
24. Total on register by sex, race and degree of vision: MRA total, as of December 31, 1963. (Number and percent.)
25. Total on register by age and degree of vision: MRA total, as of December 31, 1963. (Number and percent.)
26. Removals from register by reason for removal: each MRA State and MRA total, 1963. (Number and percent.)

Discussion

Mr. Meyer raised the question of how many new registrants were blinded through industrial accidents. Mr. Goldberg pointed out that for purposes of securing the tabulations from the MRA States, the causes of blindness had been grouped into major categories so that one could not determine from the tables exactly how many

industrial accidents there were. However, it was pointed out that since the Biometrics Branch had secured punchcards from the MRA States, the specific causes of blindness would be examined in the near future.

Dr. Graham questioned the validity of the data concerning the number of persons with light projection. Mr. Goldberg mentioned that this category of vision impairment had been underreported in the past due to the fact that physicians very often had not distinguished, at least for reporting purposes, between light perception and light projection. Therefore, prevalence data on light projection are undoubtedly understated. On new additions to the register this should be less of a problem since member States can, and presumably do, follow back for clarification when eye reports do not clearly specify which of the two categories apply. Mrs. Hatfield emphasized that some of the old eye report forms used by the MRA States were not clear in the instructions as to how light perception and light projection should be reported. In some instances the initials "LP" were used, and of course, this could mean either light projection or light perception. Mr. Goldberg stressed the importance of attempting to collect data on light projection even though it was underreported in the hope that new eye report forms being put into use with adequate instructions would encourage physicians to distinguish between the two categories in the future. Some discussion took place on the distinction in definition between light perception and light projection, and in the usefulness of each of these degrees of vision to the blind individual so affected. Mr. Meyer felt that light perception was useful vision. Dr. Graham pointed out that while this was probably true in a limited sense, light perception was not considered to be useful vision by one committee concerned with defining blindness. Mr. Goldberg pointed out that valid and reliable data on these and other degrees of visual defect will help answer questions of functional vision. Father Carroll noted the need for uniform terminology regarding useful vision in relation to mobility of the blind.

Dr. Graham suggested that the opinion of a group of ophthalmologists be obtained regard-

ing the questions raised on light perception and light projection.

In answer to questions posed by Mr. Gaines and Dr. Mac Farland, Mr. Goldberg stated that, through the annual tabulations, the MRA program will eventually provide data on trends for the various causes of blindness and characteristics of the blind population.

Mrs. Hatfield stressed the importance of uniformity in coding and in the general use and interpretation of the cause-of-blindness classification so that resultant data will be meaningful.

b. TABULATION PLANS FOR 1964 AND SUBSEQUENT YEARS

Irving D. Goldberg, Assistant Chief,
Biometrics Branch, NINDB.

Mr. Goldberg stated that with one exception the same tabulations which were completed for 1963 will be required for 1964. The titles of the tables required for 1963 were as follows:

- Table 1: First additions during 1963 by sex, age, race, and degree of vision.
- Table 2: Readditions during 1963 by sex, age, race, and degree of vision.
- Table 3: Number registered as of December 31, 1963, by sex, age, race, and degree of vision.
- Table 4: Removals from register during 1963 by sex, age, race, and reason for removal.
- Table 5: Removals from register during 1963 by degree of vision and reason for removal.
- Table 6: First additions during 1963 by sex, age, race, and major affection group.
- Table 7: First additions during 1963 by sex, age, race, and major etiology group.
- Table 8: First additions during 1963 by major affection and major etiology groups.
- Table S-1: First additions during 1963 by sex, age at registration, race, and age at loss of sight.
- Table S-2: Distribution of persons moving out of State in 1963 by new place of residence.
- Table S-3: First additions during 1963 by degree of vision and discipline of examiner.
- Table S-4: First additions during 1963 by degree of vision and major affection group.
- Table S-5: First additions during 1963 by degree of vision and major etiology group.

Of the eight regular tabulations (those numbered 1 through 8) it is planned to repeat all

for 1964 with the exception of table 5. Also, each of the five special tabulations completed for 1963 (tables S-1 through S-5) will again be required for 1964. The special tabulations are again to be completed in order to obtain some stability in the figures. Since they all represent first additions to the registers, the numbers are small in some instances and, hence, leave room for appreciable chance variation. Also, for certain items there were large numbers of unknowns in the 1963 data which limited the interpretation which could be placed on that information.

In discussing the special tabulations Mr. Goldberg emphasized certain points. With regard to table S-1 he noted that age at onset in many instances is only crude information at best. However, he indicated that age at onset information is important because it gives some idea of the delay from onset to date of report. This is of some consequence in provision of services to the blind individual as well as in the interpretation of reported incidence. He also noted that age at onset was made a required item of the Model Reporting Area in order to stimulate more complete and accurate reporting of this information. He was concerned about the fact that age at onset was unknown for a relatively high proportion of the newly reported cases in some States and very well reported in other States. He was hopeful that the States with relatively complete reporting of this information might guide other States in what they might do to obtain better reporting of age at onset information. Mr. Goldberg stressed the importance of making every effort to secure this information as accurately as possible.

With regard to table S-2 which must be completed manually by all States, Mr. Goldberg expressed the hope that the additional data from each of the States in 1964 will enable a better evaluation to be made regarding the migration of blind persons from one member State to another, the extent to which these persons become known to agencies servicing the blind persons in the new States of residence, and the extent to which first additions in a given State include duplication of individuals from a national or total MRA program point of view.

Mr. Goldberg emphasized the importance of determining the discipline of examiner for each newly reported blind person. This is of particular significance because it enables one to determine which disciplines are submitting eye examination reports and because cause-of-blindness tabulations are limited to reports from ophthalmologists or EENT specialists. He stressed that efforts be made to cut down the number of examiners falling in the category of "unknown discipline."

With regard to special tables S-4 and S-5, as well as all other tables dealing with cause of blindness, Mr. Goldberg stated that the only possible changes which may be made in the tables required for 1964 would be in the groupings of certain categories. Thus, there may be some change in the major affection and major etiology groupings, particularly in those instances where there were a large concentration of cases based on the 1963 data. If not revised in 1964 it is likely that such groupings will be revised in 1965. Mr. Goldberg also noted that consideration was being given to possible subdivision of the under 5-year age grouping in cause-of-blindness tabulations by age.

In discussing plans for "cyclical" tabulations, Mr. Goldberg stated that certain detailed regular tabulations will be prepared on a periodic basis, less frequent than annually. These will always be required in the years of the census, such as 1970, and in some cases cyclical tables will also be required for the 2 years surrounding the census year (e.g., 1969 and 1971) to give stability to the data. For purposes of trend information and to avoid gaps as long as 10 years, it is also planned to ask for limited cyclical tables in the mid-intercensal year, such as 1965. Cyclical tabulations will contain more detailed information, such as a complete breakdown by race, more detailed breakdown by age, a more detailed breakdown of causes of blindness, etc.

For 1965 causes of blindness tabulations for all persons on the register will be required. (Up to now this has been limited to first additions.) These cause-of-blindness tabulations will be similar in nature to the regular tables 6, 7, and 8 and they will be numbered 9, 10, and 11, respectively. Since data on cause of blindness for all persons on the register cannot

change appreciably from year to year, tables 9, 10, and 11 will be considered as cyclical tables and will not be required again until 1969, 1970, and 1971.

Mr. Goldberg expressed appreciation to those States which sent to the Biometrics Branch duplicate copies of their punchcards which are being utilized to plan for future tabulations and to prepare additional tables of interest. He indicated that the Biometrics Branch may again ask for a duplicate set of cards at the end of 1964.

Discussion

Mr. Meyer inquired whether discipline of examiner should be coded as ophthalmologist when reports are received from hospitals, which has been the coding practice up to now. Mr. Goldberg stated that the discipline of examiner should be coded to the person who signs the eye report and that this should represent the person who is responsible for the examination. Under usual circumstances this should be an ophthalmologist or EENT specialist. Appropriate determination should be made by each State's consulting ophthalmologist where such a problem exists.

Mr. Stocker asked a similar question with reference to out-patient clinics. Mr. Goldberg stated the situation was essentially the same. Thus, although medical students or interns may conduct the examinations, they are usually done under the supervision of certified ophthalmologists. Mr. Goldberg stated that the decision to classify the discipline of examiner as the responsible person for the examination was made up at the First Annual Conference and there has been no change in this policy. If, perchance, the eye report is not signed by the person responsible for the examination, then the determination of this must be made by the State agency and every effort must be made to properly assign to the discipline of examiner code the person actually responsible for the examination.

Mr. Bridges stated that in Louisiana they have been placing those blind persons in the leprosarium located in Carville, La., on the Louisiana register, and he wondered whether other States were also including some of these

people on their registers since those persons may not be native or resident of Louisiana. Dr. Goldstein and Mr. Goldberg indicated that the Louisiana register should contain the names of those blind persons since it is the only leprosarium available to serve leprosy patients. Apparently, the other States are not aware of any such patients who may have a permanent residence in their States.

With regard to the deadline of February 15 for submitting annual report tables to the Biometrics Branch, Mr. Goldberg emphasized that every effort should be made to meet this date which was agreed upon at the last annual conference. Those States which have difficulty in meeting that date, possibly because their time schedule is dependent upon the machine installation which prepares their tabulations, such as in Connecticut, should advise the Biometrics Branch of any possible delays and the Branch will try to work out the problem with these States accordingly.

c. FEEDBACK OF 1962 MODEL REPORTING AREA DATA

Irving D. Goldberg, Assistant Chief, Biometrics Branch, NINDB.

Mr. Goldberg advised the conferees that the 1962 Statistical Report of the Model Reporting Area was being published as a formal report of the MRA and it would be available by June 1964, at which time it would be distributed. He noted that upon receipt of the published report all preliminary reports should be discarded since the final report contains some additions and revisions.

Mr. Goldberg stated that requests from the member States for the published report varied from as few as 10 copies to as many as 500, indicating that there was some difference in the use to which the various States plan to put the Statistical Report. Apparently some States will plan to send copies of the report to each ophthalmologist, optometrist, and agency serving the blind in the State while others do not intend to make much more than a very limited intra-agency distribution. Mr. Goldberg suggested that the Statistical Report represents the fruits of the labors of each State and that it has been prepared for each State's use as it

best sees fit. He suggested that the report be used as a means of strengthening and maintaining rapport with the professional community of ophthalmologists and optometrists and with the various agencies concerned with the problems of vision impairment and blindness. By feeding the report back to such professionals and agencies, it may help to stimulate better reporting to the register and better support of the total State program. Physicians and optometrists may have an interest in the data contained in the report, particularly in the comparisons among the individual States. Further, they may appreciate the fact that the eye reports which they take the trouble to submit are being put to good use aside from the care provided to specific individuals.

The Biometrics Branch strongly suggests that meaningful tabulations be prepared by county to supplement the Annual MRA Statistical Report in the feedback of data to the professional community. This should be a simple task for States which have their registers on a punchcard system. The Branch plans to recommend in the near future the kinds of tabulations by county which may be meaningful. If any State wishes further guidance on the matter of preparing tabulations by county, the Biometrics Branch staff will be glad to provide such technical assistance.

Mr. Goldberg emphasized the importance of each State submitting its final annual tabulations to the Biometrics Branch on time in order that the Branch can prepare the final reports of the MRA without undue delay. Unfortunately, delays in submitting completed tabulations for 1962 resulted in the delayed publishing of the 1962 report. Only through the cooperation of the States in meeting the deadline for submission of their individual State reports can the Biometrics Branch prepare a timely annual report. Also, Mr. Goldberg emphasized that conscientious efforts be made to minimize the number of records with unknown information by means of follow-back to the reporting sources so that the information contained in the annual statistical reports might be of maximum benefit.

Mr. Goldberg stated that the Biometrics Branch has prepared a paper titled "Reported Incidence of Blindness in Selected States, 1962,"

which was submitted for publication in *Public Health Reports*, a journal of the Public Health Service, which has a wide circulation. He noted that this is the first time data of this kind and to this extent have ever been available in the United States. It was expected that the paper would be published within the next few months and copies would be sent to each of the States. It is planned to prepare for publication additional papers of interest from time to time, hopefully at least one such paper annually.

Discussion

Mr. Stocker asked if there were any means by which the NINDB might provide financial assistance to aid member States to complete their annual reports, particularly when additional tabulations are required or in preparing of special tabulations for feedback. Mr. Goldberg stated that monies might be available if there were a study involved in which the NINDB was a part. He noted that funds were available to assist States in having their registers put on a punchcard basis and he did not foresee any problems in meeting the MRA tabulation requirements, particularly if the States did have punchcard systems.

Mr. Gaines inquired as to whether any reports from the MRA would be published in ophthalmological journals. Mr. Goldberg stated that the aim was to publish reports in various appropriate professional journals, depending on the subject matter. Thus, papers on causes of blindness might very well be published in ophthalmological journals.

IX. OTHER BUSINESS

Dr. Goldstein announced that Mr. George F. Meyer, Executive Director, New Jersey State Commission for the Blind, was elected to the Planning Group for the Model Reporting Area by the administrators of the MRA member agencies to represent them during the next year.

Dr. Goldstein advised the conferees that the Committee on Programs for the Blind of the Council of State Directors of Vocational Rehabilitation had commended the NINDB for the work that it was doing to improve statistics on blindness through the Model Reporting Area. In addition, the editor of the *Transactions of the American Academy of Ophthalmology and Otolaryngology*, Dr. William Benedict, would, in a forthcoming editorial, commend the objectives of the Model Reporting Area program.

Dr. Goldstein emphasized that the Biometrics Branch would consider favorably any suggestions the States might have regarding items to be included in the agenda for the next annual conference. In particular, the Biometrics Branch would be interested in having presented any surveys or studies which the States had conducted. Ideas for making the conferences as productive as possible would be welcome.

In conclusion, Dr. Goldstein conveyed the thanks of the Model Reporting Area to the North Carolina State Commission for the Blind for its warm hospitality throughout the Conference.

The Conference adjourned at 12:30 p.m. on May 15, 1964.

APPENDIX A

Predictors of Blindness in Diabetes

Leo H. Riley, M.D.¹

This presentation deals with a research project currently in progress. No results are available as yet, but because the study is an example of the use of a blindness register as a research tool, the study design is being discussed at this Conference.

Last month in the *New England Journal of Medicine*, Dr. David Cogan pointed out that about 10 percent of all blindness in the United States is due to diabetes, and that many blind diabetics are young adults, a fact which gives rise to a major socioeconomic problem. At St. Paul's Rehabilitation Center for the Blind, approximately one-half of the trainees have been diabetics.

Our preliminary investigations of these diabetics at St. Paul's have led us to the present study. Our experience with them has not confirmed the statements in the literature about relationships between the severity of diabetes and blindness, nor about poor control and blindness, nor even about pituitary suppression and blindness. A person is said to be in "poor control" if the level of sugar in his blood is not maintained within certain arbitrary limits because of either improper amount of insulin, improper amount of exercise, or an incorrect diet. The theory of suppressing the pituitary gland, located at the base of the brain, is based on the fact that some years ago a diabetic who lost her pituitary function after a pregnancy, enjoyed a spontaneous improvement in her diabetes. Since that time, suppression of the pituitary gland through the use of X-ray treatment has had fairly good results overall, except that at St. Paul's we see the failures. This is

why I say that our experience has not supported what one reads in the literature about pituitary suppression with reference to diabetes.

Perhaps these trainees did not constitute a valid sample of blind diabetics and our observations were worthless outside of St. Paul's. Where could we get a better sample? We thought of conducting a study on all Joslin Clinic diabetics, that is, a comparison of the characteristics of those who become blind with those who do not become blind. The Joslin Clinic is the leading single source of referrals of blind trainees to St. Paul's, and excellent relations exist between the two agencies. We were assured of their cooperation by Dr. Howard Root, Medical Director of the Joslin Clinic. But we quickly realized that because of the reputation of the Clinic as a leader in the field of diabetes, many diabetics go to the Joslin Clinic after years of treatment elsewhere because of diabetic retinopathy.

We would have to eliminate this source of bias if we were to proceed with our plan. Dr. Brian MacMahon, Professor of Epidemiology at the Harvard School of Public Health, solved this problem by pointing out a device previously used on a study of cancer and diabetes by using only those patients who came to the Joslin Clinic within 1 year of their diagnosis of diabetes.

We also decided to limit the study to persons residing in Massachusetts so that we could take advantage of the Massachusetts Blindness Register as a research tool. There was no record at the Clinic of all their blind diabetics, although they do have a list of all the cases with retinopathy, however mild.

¹ Director, American Center for Research in Blindness and Rehabilitation.

At that time, with the cooperation of Mr. John Mungovan, Director of the Massachusetts Division of the Blind, we found 769 cases registered as blinded because of diabetes. Of these, 216 were also registered at the Joslin Clinic, but only 99 had been treated there within 1 year of their diagnosis of diabetes. Further search at the Massachusetts Division of the Blind yielded 1,229 cases who had died. Of these, 290 had been patients at the Joslin Clinic but only 86 had been treated within 1 year of their diagnosis. Dr. MacMahon suggested that we limit the study to the 25-year period, 1930 through 1954. Therefore, the sample of 185, 99 living and 86 dead, was reduced to 158, 88 living and 70 dead. These last 158 persons then constituted the study population. It included 83 males, 43 living and 40 dead, and 75 females, 45 living and 30 dead. Each case was matched with a sighted control case by the following criteria: date of birth within 5 years of index case, sex, Massachusetts resident at last known address, treated at Joslin Clinic within 1 year of diagnosis of diabetes and living on the date of blindness registration of index case.

All cases were identified by their Joslin Clinic case number. The search for the first matching case was carried on by looking forward by case number, the second by going backward, and so on, alternately. In this way, each matched case was selected from persons who were first seen at the Clinic about the same time as the index case, and the biases of having all the matching cases first seen later than the index case was avoided.

The next decision involved the type of study to be done. I wanted to answer some specific questions which had come up during my tenure at St. Paul's, but Dr. MacMahon felt that a broad, descriptive study was indicated as well. Accordingly, we looked over the records at the Joslin Clinic to see what data were available for comparison throughout the 25-year period, 1930-54. We found many items that seemed to be recorded adequately on most charts, and prepared our data sheets accordingly.

When all the data have been gathered between the study groups they will be analyzed for

significant differences between the study group and the control group. Also, the study should indicate information for further research. In addition to this study of the matched pairs, we will compare the entire group of blind diabetics with all other Massachusetts diabetics at the Clinic in an attempt to answer some specific questions.

For example, does the incidence of blindness in diabetics vary by sex? Although diabetes is more prevalent in females, the incidence of blindness has been greater in males both in this study and at St. Paul's.

Does age at onset of blindness divide our study group into two populations, or is there a continuum? The earlier onset of blindness in juvenile diabetics suggests that there may be two populations.

Is delay in diagnosis a factor in blindness? The date of onset minus date of diagnosis, which equals "delay in diagnosis," will be defined as the time lapse between the onset of symptoms and the date of diagnosis as recorded on each chart.

Is poor control a significant factor in the development of blindness? Also, is the severity of the disease a factor in blindness?

Discussion

To questions posed by Dr. Quade and Mr. Hanson with respect to the poor control of diabetes, Dr. Riley stated that he felt that data on the control of diabetes was quite adequate. Records are made of level of blood sugar in each case and are tested every 24 hours. Dr. Riley mentioned that there had been a report made of blindness as a result of poor control, but there were some who questioned the report. It was felt that one was apt to come to the conclusion that blindness resulted from poor control of diabetes if one looked only at the blind. Before any conclusions may be drawn as to blindness resulting from poor control of diabetes, Dr. Riley felt that any study on this subject should include diabetics who had poor control but did not become blind.

In response to another question by Mr. Hanson, Dr. Riley stated that while the use of various weights based on clinical features of diabetes may have proved useful as a predictor of

outcome on an original study group, it was questionable whether the same weights would be useful for any other group of diabetics.

Mr. Meyer questioned Dr. Riley as to how a blindness agency might test the vocational ability of a diabetic before rehabilitation was

undertaken. Dr. Riley mentioned that there was still much to be learned about blind diabetics and that at this point in time there was no set of rules by which the vocational ability of a blind diabetic could be predicted before rehabilitation was begun.

APPENDIX B

California Hopes for Coordinated Use of a Register

William D. Simmons¹

California does not have a register of the blind. The needs for information on the amount and distribution of blindness, on the causes of blindness and the nature of the blind population have been satisfied by a variety of means through the years. Some random examples of these means are: infectious diseases (which could cause blindness) are reportable to the State Health Department; blind children in public school programs are counted annually by the State Department of Education in order to receive the quota of braille books from the American Printing House for the Blind; periodic studies of the social characteristics of blind aid recipients are made by the State Department of Social Welfare; the State Health Department publishes studies on the occurrence of blindness in the California population using information derived from school, rehabilitation, welfare, and health survey records.

At the same time that small, selected, and meticulous studies have been carried out and published, for example, on medically insured groups, labor union members, and on recipients of geriatric clinic services, large scale and inevitably less precise studies such as the California Health Survey which covered more than 10,000 households have been done and information on the amount of blindness and visual impairment published. The data do not always correspond since the definitions differ.

It would appear that there is some justification for improving what is known about blindness and the blind population in California in order to avoid duplication of effort and to serve the needs of the several departments and

agencies providing services and developing programs.

Just about the time that blindness reporting became a topic for thinking about, two events provided some real impetus for taking the step of actually talking about reporting. One of these events was a request from our State Department of Social Welfare for a figure representing the "universe of operable cataracts." This was in connection with budgeting for what appeared to be a mounting number of cases processed for surgery under the Medical Care program. In 1 year the number of cataract surgeries doubled. It increased in the next year and by another 50 percent in the following year. At stake were such important considerations as selection criteria for surgery as well as appropriations. One may be excused for reeling a bit when asked for the "universe of operable cataracts." We took the number of cataracts reported by household respondents in the state-wide health survey, and used the rate for those aged 65 and over who had annual incomes under \$2,000. Then we modified this figure in line with information from a one-county study of the health of OAS applicants using the rate for cataract where that was listed as the "principle diagnosis." After that sleight of hand it came easy to make one further guess—the percentage of cataracts considered operable by professional judgment—to provide the gospel on which legislative action will be based.

Not long ago a worried hospital administrator asked if cases of retrothalental fibroplasia (RLF) were again appearing. Apprehensively we said they were not. Apprehensively because the only reporting of RLF was a purely voluntary one from agencies which provided services and

¹ Head, Prevention of Blindness Program, California Department of Public Health.

counseling to the parents of young blind children, usually about the time they were of training age. This is not very helpful for control measures. As an incidental part of this matter we wondered if the inquiry represented confusion between retrolental fibroplasia and retinoblastoma because there has been talk that retinoblastoma has increased as a cause of blindness among preschool children.

At any rate the subject of blindness reporting now has undeniable pertinence. The needs of several State departments could be served by replacing the present spotty and uncoordinated systems of data collecting in order to present a picture of blindness in California more adequate for program development and emphasis. In a State the size and complexion of California with respect to medical care, special services, and mobility of population, there are immense problems connected with the establishment of a register of the blind. We estimate that there are about 35,000 blind persons in California.

In mulling over the ways to set up the problems so that they could be studied, I decided to draft a simple questionnaire to be sent initially to the working level program people in the various State agencies which have services of one kind or another for blind individuals.

The questions asked whether or not the agency collected information on blindness, what information is collected and how, how often the information is brought up to date on an individual, and in what form it is maintained. Also the questionnaire was used to determine how complete the information is felt to be both as to individual and numbers of missed persons; and what peculiarities the information has, that is, possible inaccuracies, selection of individuals, etc.

A second question asked whether or not specific information could be provided from the data presently collected and with what limitations if a blindness register were developed.

A third question asked about the uses which might be made of information gathered in a reporting operation if such were developed. A memorandum accompanying the questionnaire provided considerable specific detail on how a

register might operate and what information could potentially be gathered.

The fourth and last question polled the willingness of the various departments to discuss further the needs for blindness reporting and the possible means for supporting such an operation.

Services to the blind represented in the returns to this questionnaire were: home counseling services for preschool children, special education in the public schools of California, rehabilitation services, home teaching and counseling services for the adult blind, library services for the blind, the orientation center, sheltered workshops and industries for the blind, and the welfare programs for the blind. Each of these program units in State government now collect some information on blind individuals. Variety in the type of information collected is not as great as was anticipated. Since each deals with a select part of the blind population some peculiarities in the data are apparent. Within these limitations, however, the services generally felt the information to be quite complete. All agencies agreed that there would be little problem administratively in making the data available to a register. Most hopefully all agencies agreed that if reporting were to be developed in the State the information would be useful and they were willing to discuss further the possible means of support.

In attempting to answer in what ways reported information would be of use, there was more of a problem. Aside from a vague feeling that some presently impossible comparisons might be made between caseloads and a total population of blind individuals, there was not much perception of the ways in which this information tool might be used in program development and evaluation. The most common argument advanced against a register was that the sample represented by the operating programs is sufficiently large to validate causes of blindness and characteristics of the blind population. Another common concern was that physicians would be unwilling to report or at best would provide such poor response that conclusions based on the information would be highly inaccurate.

Fortunately there is a readymade way to establish now with all of these services the discussion which they committed themselves to undertake. Some 12 years ago the California legislature established by statute an Interdepartmental Coordinating Council on State Programs for the Blind and required it to meet regularly and to render reports. The directors of the departments of education, health, rehabilitation, and welfare, make up its membership. The working committee of this council is made up of those who provide State services for the blind. It meets frequently, acts as a coordinating group for all services to the blind, and develops the items for discussion, decision, and presentation to the legislature by the council of directors.

It is in these two groups that preliminary discussions of blindness reporting have been brought up. Accustomed to coordinating their wide range of services and programs for the blind I think it likely that the agencies would be willing to consider, beyond the program uses, some aspects of reporting which are less familiar to them. One is the value of, and absolute necessity of, using the information for professional education. Failure to use the register to report back to physicians will prejudice its chances for successful operation. More important, it neglects the responsibility to keep practicing physicians up to date on information of practical interest to them which they cannot get in any other way. Since our service programs are fairly good, extension of services would not be the primary focus of a register in

California. It becomes all the more important to provide other information perceived as vital to practicing physicians. Related to the crucial problem of physician acceptance in a State not noted for this is another aspect of reporting unfamiliar to service programs. This is the value of having medical information collected, correlated, and interpreted by a medically oriented agency with experience in handling medical data for research purposes. From the standpoint of control and prevention the most urgently needed information on blindness is epidemiological. It is on this basis that the health department has accepted for the time being leadership in exploring coordinated use of reporting and registration of blindness.

Discussion

In response to a question by Mr. Gaines, Mr. Simmons mentioned that data on blind clients in California were obtained from all agencies serving the blind only when the Department of Health was conducting a specific study on the blind. He mentioned that although each agency used its own eye report form, each form asked for approximately the same information.

Mr. Meyer mentioned that in an effort to co-ordinate the private agencies, the private agencies be invited to be represented on the co-ordinating council of State programs on blindness. Mr. Simmons mentioned that the work of private agencies in California was not significant and those persons served by the private agencies were also known and served by the public agencies.

APPENDIX C

Study of Attitudes, Awareness, and Performance of Blindness Reporting Sources

Richard E. Onken ¹

Since we are currently in the early stages of this study—at this point, we are involved in developing our interview questionnaire—and also since some of you here today will be interviewed in the course of this study, I will present only a short summary. I do want to thank those of you who were selected to participate in this study and who have already expressed your cooperation. These States are: Massachusetts, Rhode Island, New York, Virginia, Louisiana, Ohio, Kansas, and Oregon.

The aim of this study is to investigate the awareness of, attitudes toward, and reporting performance regarding State registration of the blind on the part of ophthalmologists, EENT specialists, and optometrists. The study will also aid the Model Reporting Area for Blindness Statistics (MRA) by providing information which will help it solve an important problem in making registers more complete.

The basic objectives of the MRA are: (1) To make better statistics available on blind persons, and (2) to stimulate research in the field of blindness.² To achieve the first of these objectives, the MRA is encouraging complete reporting of blind persons by ophthalmologists, EENT specialists, and optometrists. Without such reporting, State registers of blindness can never satisfactorily perform their intended functions, for example, helping to plan and provide services for blind persons, to plan agency budgets, evaluate service programs, and

to serve as a research tool. What is needed, therefore, is systematic study of reporting and nonreporting of blindness. In order to help the Model Reporting Area as well as nonmember States in obtaining maximum cooperation from ophthalmologists and optometrists, it is proposed to measure the extent to which these potential reporting sources cooperate with State agencies. Specifically, of interest will be the actual behavior of ophthalmologists and optometrists (that is, the extent to which they report or fail to report) as well as their awareness of and attitudes regarding the reporting of blind persons. But since reporting practices and attitudes depend not only on those who do the reporting but also on those who collect reports, State registration agencies' efforts to encourage reporting, and particularly the communication which has evolved between these agencies and ophthalmologists and optometrists, will also be studied.

This study, unlike others discussed during the Conference, is a study of registers rather than a study which either uses register information or the blind persons registered as a source of respondents. The study is also an example of applied research. That is, it is designed to examine an immediate problem, the reporting of blind persons to a register. However, it is not only important to describe the awareness, performance, and attitudes of blindness reporting sources in order to identify the problem, but it is also essential to understand why potential reporting sources do or do not report a blind person whom they have examined. Therefore, we hope that the findings of this

¹ Research Assistant, American Foundation for the Blind.

² The Model Reporting Area for Blindness Statistics, U.S. Department of Health, Education, and Welfare, U.S. Public Health Service Publication No. 1003, Washington, D.C., 1963.

study can be utilized in order to improve reporting.

At the next Annual Conference, hopefully, there will be presented a final report rather than a preliminary report.

I hope this gives you some idea what the study is about and if there are any comments or ques-

tions about the study, I would be glad to answer them at this point.

I would like to say to those of you who have been contacted and who have expressed their willingness to cooperate, that we will be in touch with you in about a month to make final arrangements for the field phase of the study.

APPENDIX D

Problems in Studying Blind People

Eric Josephson, Ph. D.¹

There are many ways of studying blindness and blind people. One approach is illustrated by the tabulations emanating from the Model Reporting Area for Blindness Statistics. Another method is to contact blind people directly and to observe or interview them. The trouble is that they are relatively few in number and widely scattered about the landscape. How then can we find them?

One technique is quite familiar to you: the use of State blindness registers as a means of sampling the blind population. A second source consists of lists or rosters maintained by private agencies serving blind people; in some instances they are more complete than State registers. And a third way of finding blind people does not require a register or list; rather, it involves screening a sample of all households in a community to determine the presence or absence of blindness and other visual impairments. This is the kind of study that the American Foundation for the Blind and Western Reserve University recently conducted in Cleveland, Ohio. Today I shall present some findings from this study which may be of interest to you.

The primary aims of our study were to determine whether a telephone sample yields prevalence rates of visual impairment which are comparable to figures obtained by more traditional sampling methods (i.e., all households); to discover whether telephone interviewing provides reliable data about the presence of visual impairment, or whether there is underreporting when results are compared with face-to-face interviewing; and to determine whether reliable vision tests can be administered in homes by nonmedical interviewers.

I should explain that this was not a study of legally blind persons alone. We adopted the functional criteria for defining visual impairment which have been employed by the National Health Survey (NHS). That is, we interpreted "visual impairment" to include all persons who reported serious trouble seeing, even wearing glasses, and "severe impairment" to include all persons who replied negatively to the question, "Can you see well enough to read ordinary newspaper print with glasses?" The Health Survey has estimated that there are approximately 3½ million visually impaired persons in the United States of whom nearly 1 million have severely impaired vision.¹

In devising a strategy for locating cases of visual impairment, our assumption was that a fairly large sample of households would be essential to determine the magnitude of the condition and also to provide a representative number of cases for analysis. Without such a sample, we would have missed both the "hidden" or unknown blind and the far greater number of persons who have severely impaired eyesight but are not regarded as blind.

In most States and large cities those who become known to and listed by social agencies are chiefly blind persons receiving public assistance or people getting special services. As a result, bias exists in such lists, and we may assume that an important minority of the total blind population are unaccounted for because agencies have been unable to reach them, because they do not want to be reached, or because they do not know they are blind. One of our aims was to test a method for getting information about this hidden group. As for visually impaired persons who are not regarded as blind, since no

¹ Research Associate, American Foundation for the Blind.

list or registration of such cases exists, there is no way to reach them other than through a household sample.

But in view of the relatively low prevalence of visual impairment and the large number of persons to be screened, a household sampling based entirely on personal visits would have been prohibitively expensive. An alternative approach, and the one we followed, was to rely chiefly but not exclusively on a telephone screening of households. Would such an approach introduce bias into the sample? In cities like Cleveland, more than three-fourths of all households have telephones. And a special study which we made of 180 legally blind persons drawn at random from the client list of the Cleveland Society for the Blind (the leading local private organization concerned with the welfare of blind persons) showed that the proportion of blind persons with telephones was approximately the same as in the general population. In other words, a telephone sample was unlikely to discriminate against the blind.

What we did in Cleveland then was to draw a random sample of nearly 3,700 households from the most recent Cleveland city directory; it split into a telephone sample of approximately 2,800 homes and a nonphone sample (including unlisted numbers) of 900 households. All telephone listings were assigned to interviewers for screening, but we decided to sub-sample approximately one-third (309) of the nontelephone listings. Screening questionnaires, identical in both samples, contained a checklist of health items adapted from the National Health Survey, including "serious trouble seeing even when wearing glasses." Interviews were conducted with persons reported in the screening (either by themselves or by other family members) as having serious trouble seeing. These interviews provided measures of the severity of visual impairment, including subjective appraisals by respondents and actual tests of visual acuity (which were administered with the aid of the 10-foot Sloan letters chart and the Leibenson near-vision card). Respondents who said they had been examined within the past 3 years were asked to sign releases authorizing us to approach their doctors

for additional information, and a few persons who had not been examined during this period were invited to have clinical examinations at our expense.

In our total sample (telephone and nontelephone) the prevalence of all cases of visual impairment (23.8 per thousand) was fairly close to the NHS figure (19.8 per thousand). In our telephone sample the rate was even closer (19.3 per thousand) but in the nontelephone group the prevalence was nearly twice as high (37.5 per thousand). This may have resulted from the fact that nontelephone households scored low on socioeconomic measures; we have reason to believe that the visually impaired in general are economically underprivileged.

The various measures of visual impairment which we obtained—our own tests of near and distance acuity, answers to a series of questions about visually impaired respondents' trouble seeing, reports from physicians—gave us an opportunity to correlate what people told us about their impairment and actual tests of vision. Slightly more than one-quarter (26 percent) of our visually impaired respondents said they were unable to read newspaper print even with glasses (the criterion by which NHS identifies its "severely" impaired population). NHS itself reports that an almost identical proportion (28 percent) of all persons with visual impairments fall into this category. However, one-fifth of our respondents who said they were unable to read newspaper print were able to read 8-point (standard newsprint) or smaller type in the Jaeger near-vision test. Conversely, almost one-fourth of those who said they were able to read newsprint could not read 8-point type on the Jaeger test. This is not conclusive evidence of unreliability in NHS criteria for defining severe impairment, especially since our near-vision test was administered at 14 inches and NHS does not specify distance in its question regarding ability to read newsprint. Nevertheless, it suggests that any definition of severe impairment based entirely on what people say is subject to error.

To identify the blind, we relied on our own test of distance acuity: all respondents who tested at 20/200 or less were considered blind. We found that 10 percent fell into this cate-

gory—a figure which would have been expected from the proportion of estimated blindness in Cleveland (2 per thousand) in the total universe of visual impairment as defined by NHS (19.8 per thousand).

We found relatively little agreement between the results of our own vision tests and what physicians reported. Furthermore, we found that our interviewers consistently recorded more visual impairment than did the medical reports. What explains such discrepancies? It must be observed that our tests were not intended as substitutes for clinical examinations. Although reporting physicians suggested that many patients had underestimated the time which had elapsed since their most recent visit, there is no evidence from our study that the inconsistency between our tests and what physicians reported was caused by the time lag between their examinations and our tests. There is reason to believe, however, that physicians differ in vision-testing procedures, not only as compared with our own household examinations but among themselves as well. Thus we can make no definitive statement about the reliability of our vision-testing procedures or of the physicians' reports. However, we feel that our fairly simple vision tests achieved at least one objective—a check against self-reported disability. In any case, these tests were not as unreliable as one might have suspected; they can be done in the home.

Personal interviews with visually impaired persons in our sample yielded much data about the impact which trouble seeing has had on their lives. As might have been expected, characteristics and behavior varied significantly according to the severity of visual impairment. Thus, as compared with the moderately impaired (persons who reported serious trouble seeing but who could read newsprint with glasses), severely impaired persons (those who said they could not read newsprint with glasses) were older, more likely to have first experienced trouble seeing late in life and to suffer from other chronic conditions, more limited in mobility, less likely to be working, and less actively engaged in ordinary leisure pursuits (reading, watching TV, visiting friends, joining clubs, etc.).

I shall turn now to the problem of services. What do visually impaired persons receive in the way of medical and social services and what do they need? Perhaps our most striking finding in this connection is that so many receive no services whatsoever and apparently feel no need for help. More than half of our respondents said they received no medical or social services from public or private agencies in Cleveland, and nearly half said they needed no services because of their trouble seeing.² It is worth noting that the degree of visual impairment made little difference as far as services are concerned. The proportions of severely and moderately impaired persons receiving and expressing a need for particular services was approximately the same. As for the kinds of assistance which our respondents get, general medical treatment was first in importance, followed by visits from social workers, glasses and optical aids, etc. Severely impaired persons in our sample were more likely to be receiving agency help of some kind, e.g., visits from social workers, or planned recreation. This group also expressed a greater need for assistance in reading, traveling, housework, and shopping—precisely the activities in which serious visual loss is most likely to make itself felt.

In Cleveland legally blind residents are offered vocational, recreational, and other special services by the Society for the Blind. Less severely impaired persons have no such single agency concerned with problems stemming from their impairment; if they need help they must obtain it from a large number of less specialized health and welfare agencies in the metropolitan area. It is not surprising, therefore, that when asked to name "any agency or organization in Cleveland that provides services for people who have trouble seeing," the great majority of our respondents failed to mention the Cleveland Society for the Blind. More striking, half of our legally blind respondents failed to mention the Society; that is, they claimed that they did not know of any institution providing services for them. However, when we subsequently asked our respondents, "Have you

²The two figures are not mutually exclusive; that is, some who presently receive no services expressed a need for aid, while others who are getting help mentioned additional services they would like to get.

ever heard of the Cleveland Society for the Blind?" 9 out of 10 indicated that they had. In other words, it turned out that most of the people in our sample did know of this agency but only after having their memories refreshed.

Lack of awareness (particularly among the severely impaired) of the Society's existence is related in turn to the fact that the Society itself is not familiar with all blind persons in Cleveland.³ Of the 14 legally blind persons in our sample, fewer than half were known to the Society for the Blind. The remainder—i.e., blind persons unknown to the Society—we have tentatively classified as "hidden." This high proportion of unknown blind persons may well have been due to the extremely small sample of legally blind people which our household screening uncovered; in view of the fact that the Society knows approximately two out of three blind residents in metropolitan Cleveland, it is doubtful whether we would expect to find such a large proportion of hidden blind persons in a larger household sample.

Who are the hidden blind? Our limited data suggest that they are older than known blind persons and also more likely to have first experienced blindness in middle or later years. As may be expected, our unknown blind respondents were unlikely to be familiar with the Cleveland Society for the Blind—only half of them naming it when asked whether they knew any agency that provided services to blind residents. In contrast to the known blind, who receive many social and medical services, hidden blind persons apparently get little help; nevertheless, half of them in our sample expressed a need for such services. One kind of assistance they may need is treatment for their eyes; they were much less likely to have been examined recently than the known blind. Another problem for the hidden blind is mobility, since they were just as limited in this respect as were the known blind. Indeed, our data suggest that the health of unknown blind persons is even poorer than that of their neighbors known to the Society—i.e., they themselves were more

likely to rate it as poor and also more likely to report a multiplicity of chronic conditions and ailments.

Again, these differences between the two groups are extremely tentative; whether a larger study would confirm them remains to be seen. In future research we hope to make detailed comparisons of the known and unknown blind, particularly their respective adjustments to blindness. Thus, we assume that some blind people remain unknown because local agencies lack the resources to find them; others, however, may conceal their condition from all but immediate family and close friends because they do not wish to be associated with "the blind." Why? Unfortunately, our study in Cleveland produced too few cases of blindness, let alone hidden blindness, for systematic analysis of such problems.

These are some of the results of our Cleveland study. What are their implications for you? One thing is obvious: to look for blind people by visiting and screening every household in a community would be prohibitively expensive. But the strategy which we adopted—a sample study of a city population—is also very expensive and complicated as well. On the other hand, since no register can ever be 100 percent complete, I don't know of any other way to track down the missing blind people—a very important group from the point of view of planning services and also of research.

But even if State registers can never become 100 percent complete, they will probably remain our most important source from which to draw samples of the blind population. Now this creates problems for you and before closing I want to discuss some of them with you.

The first point I want to make has to do with the nature of sampling studies. As I said earlier, we draw samples because it would be too expensive to undertake a study of all blind people living in any State and also because for good statistical reasons it is not necessary to do so. But if we are to draw a representative sample from a register, that sample has to meet certain criteria. For example, if it is to be a random sample, every blind person on the register must have an equal chance of being drawn or selected. What this means in practical terms

³ The Cleveland Society for the Blind maintains a list (for mailing purposes) of slightly more than 2,000 blind residents of metropolitan Cleveland and provides services to less than half that number. The estimated total blind population of the area is well over 3,000.

is that if any attempt is made by the State agency or by the researchers themselves to influence the chances that a client has to fall into the sample, then the results will be biased. What I am describing is a fundamental principle in this kind of research. Any State agency that agrees to make its register available for sampling purposes should therefore not attempt to preselect or screen the clients to be studied.

But this in turn leads to other problems. One of them—which is very close to all of you—has to do with the protection of your clients' privacy. After all, this is not only your duty; in certain cases you are obliged to do so by law and to obtain the necessary clearance from clients themselves. Now some people feel strongly that the kind of research I have been talking about represents an invasion of privacy. Indeed, as we learned at last year's meeting, some people feel that registration itself is an invasion of privacy; yet all of you here today adhere to the principle of registering blind people in your States. Are interviews then also to be regarded as invasions of privacy? Some of your clients may think so. But if they do, they have the right to refuse to be interviewed when approached. What I am urging is that it should be left to them to decide.

As a matter of fact, our experience in various studies shows that most blind people can hardly wait until the interviewers come to visit them, enjoy the interviews very much, and are reluctant to end them. As you know, many of them lead lonely lives and a visit from an interviewer may brighten their day. Nevertheless, I want to stress that we have as much interest in protecting your clients' privacy as you do. What they tell us is always confidential; names are never associated with answers to particular questions. The reason for this is that we are interested not so much in what Mr. X may have to tell us but in what all of our respondents together have to report.

What I am saying boils down to this: people who engage in research on blindness or any other social problem have professional standards, just as you do. Part of our professional code includes a guarantee of anonymity to respondents, so that people who talk with us may feel absolutely free to speak their minds with-

out any fear that what they say will be associated with them personally.

Another point I wish to make has to do with the obvious burden imposed on you by such research efforts. It is a fact that a number of States, some inside and some outside the Model Reporting Area, have had to meet many requests for help by researchers. Some States have been approached more than others. Now this is a credit to those States and to the manner in which they have developed statistics on blindness. But of course, to administrators of State agencies, our requests for cooperation may seem to be less of a credit than a nuisance. I appreciate the importance of the fatigue factor here; most of you are probably shorthanded. But I don't know anybody engaged in research on blindness who would not do everything in his power to interfere with your work as little as possible and to take responsibility for as many of the petty details as possible. Furthermore, I think that as the Model Reporting Area grows, as more States raise their standards of recording and reporting blindness statistics, the burden of requests for help on research projects will be spread more equitably—which means that for some States the load will grow lighter. At any rate, let us hope so.

This leads me to still another point. As Dr. Goldstein pointed out in another meeting a few months ago, registers and their data represent a most important research tool. Indeed, I take it that one of the objectives of the Model Reporting Area is to facilitate research on blindness. But what kind of research are we talking about? Sometimes we are asked to deal with practical problems of direct concern to you and your agencies. You would like to know more precisely what your clients' characteristics are, what they need in the way of services, and how your programs should be changed to meet their needs. For example, how many nonreaders among the blind might be helped by the regional library programs? This kind of "market" research will and must continue.

But there is another and equally important kind of research which deals with more fundamental aspects of blindness as a social and psychological phenomenon. To illustrate, some

of us would like to analyze the impact of adventitious blindness on the personality of those whom it strikes. At first glance, such studies may not appear to offer immediate results. But sometimes it is precisely this kind of basic research that pays off most in the end. I say this because, as you have often heard, although blindness has been with us for many centuries and there is a vast literature about the subject, it is astonishing how much more there is to be learned. If you take this longer view of research needs, I am sure you will agree that the more we learn about blindness and its consequences, the better—for blind people themselves and for the agencies that serve them.

If we are to achieve this goal, we need your cooperation. I think we can be of some help to you; and you, obviously, can be of considerable help to us. As a matter of fact, we cannot undertake large-scale studies of blind peo-

ple without your help. In appealing for more cooperation between your agencies and people doing research on blindness, I am not just speaking for organizations such as the American Foundation for the Blind but also for scholars in colleges and universities and other institutions not even connected with the welfare of the blind. In the interest of learning more about blindness, such efforts by “outsiders” need the maximum possible encouragement. If they are discouraged from doing research in this field, we will all be the losers.

In closing let me say that together, I am sure, we can work out the many problems of conducting blindness research based on your registers; together we can explore new frontiers of research on blindness—not only to increase knowledge but to insure that blind people themselves will be the beneficiaries of that knowledge.

APPENDIX E

Proposed Pilot MRA Register in Egypt

Hyman Goldstein, Ph. D.¹

The activities of the Model Reporting Area and the publications that derive from them, are having an impact in this country and throughout the world and will continue to do so. The Proceedings of the First Conference were distributed through normal channels and part of these normal channels involve distribution to the overseas offices of the NIH Office of International Research. Its Paris office, after receiving and reviewing the Proceedings of the First Conference, notified me of its great interest in seeing that a model reporting register for blindness be established in one or more of the countries within its jurisdiction, particularly in Egypt, which has a serious blindness problem. The Director of the Paris office came to Bethesda and met with Dr. Masland, Director, NINDB, and with me. He indicated his interest in pursuing the matter. As a result, a letter was dispatched by Dr. Masland to the Egyptian Government, informing it of the establishment of the Model Reporting Area in this country and stating that it would be his pleasure to have me visit with their ophthalmologists and research scientists to determine the feasibility of such a project. Several months later I was informed through the NIH Paris office that the Egyptian Government had invited me to visit the country and discuss the matter. This trip was made early in February. I am scheduled to return there again this fall to help put the project into effect.

The objective of this blindness register demonstration project in Egypt is to ascertain the feasibility of developing and utilizing a blindness register in a community as a mechanism for

producing statistics on blindness needed for prevention and control activities.

The project is concerned with the procedures necessary to establish a blindness register by securing cooperation of reporting sources and blindness agencies, by reaching agreement on a uniform definition of blindness, on the essential items of information to be reported, by setting up a mechanism for continuous and periodic updating of the register in order to remove those persons who have died, have recovered sight, have moved out of the community, or who have been lost to followup. Finally, by utilizing machine-processing methods, tabulations by cause, visual acuity, and demographic and other characteristics of the blind may be readily and accurately produced. The methodology and procedures that will be developed may serve as a model for similar effort in larger geographic units at a later date.

From statistics that have been published in the past, mainly from data secured in connection with the census of the population, it would appear that the blindness prevalence rate in Egypt, as determined by census, is one of the highest in the world. The 1960 census of Egypt yielded a population of about 26 million people. It is obvious that in a census of this type or even a representative adequate sample of this population, one is not able to secure either visual acuity or cause data with which to validate the statements of blindness from the population being enumerated, and thus not able to arrive at rates of blindness and severe visual impairment due to specific causes for specific population groups by age, sex, and other demographic variables. It should be mentioned that in a census of the blind, the extent to which the rate

¹ Chief, Biometrics Branch, National Institute of Neurological Diseases and Blindness.

is overstated or understated cannot even be estimated with any degree of certainty. In the United States, attempts by the Bureau of the Census over a 110-year period to collect statistics on blindness through use of the decennial census, failed. Details of this are given in a publication of the Biometrics Branch called, "The Model Reporting Area for Blindness Statistics" and published in the summer 1962 issue of *Sight-Saving Review*.

Under such circumstances, it seemed obvious that establishing a registration procedure in Egypt, such as is now in existence in England and Wales, Canada, Sweden, and in many States in this country, offered some possibility of validating the data on blindness with visual acuity and medical data and thus arriving at meaningful rates that would permit a preventive approach to the blindness problem. In view of the fact that completeness of registration is dependent on the completeness of reporting, a rate based on registration is understated to the degree of underreporting. The degree of underreporting can be ascertained fairly reliably by periodic house-to-house sample surveys accompanied by an examination in an ophthalmological clinic of all or of a sample of those picked up as seriously visually impaired by the survey. This will make possible the determination of which demographic groups may be underreported, and thus assist an educational campaign to be directed to the achievement of early examination and diagnosis and to improved reporting.

Obviously, a mechanism to generate valid statistics on the incidence and prevalence of blindness on a continuing basis would be ideal. Although an approach to this desideratum has been made in the countries mentioned above, it is evident that a procedure found to be suitable in one country may not be so in another for various reasons. Thus, it was proposed that a demonstration project, based on development of a blindness register, be established in a community or district in Egypt, preferably with a population of between 200,000 and 300,000.

The visit to Egypt was made in company with the Administrative Officer of the Paris NIH office. We met with the Secretary-General of the Egyptian Medical Research Council, which

tries to coordinate medical research in Egypt and reviews all requests from universities or Egyptian federal agencies that are submitted to the Ministry of Scientific Research, of which it is a part, for medical research support. This included proposals utilizing Public Law 480 or counterpart funds, which would be the funding mechanism for the project under consideration. Such funds are American-owned foreign currency. As a matter of fact, the Medical Research Council has become increasingly interested in the development and negotiation of collaborative research projects under the Public Law 480 program. The Medical Research Council has under its jurisdiction a number of research institutes. One that is projected for the near future is an ophthalmological research institute under the direction of Dr. A. M. Soliman, a leading ophthalmologist. It was believed that Dr. Soliman, as principal investigator, might provide the best means of getting such a project under way.

The present definition of blindness in Egypt is an inability to see or count fingers at one meter, and this is equivalent to Snellen distance vision measurement of approximately 3/200. Dr. Soliman indicated to me that this definition would be changed to 6/60 in order to agree with the international definition. A visual field restriction of 20° for vision of better than 6/60 would be incorporated into the definition. It should be observed that 6/60 visual acuity is equivalent to our 20/200 visual acuity in this country. Dr. Soliman appeared agreeable to use the American version of the Standard Classification rather than the international version due to the following factors: (1) It is possible to convert tabulations from the American Classification to the international one, but not vice versa, very easily; (2) the American Classification has an accompanying Index and there is work at present on the preparation of the Manual to go along with it; (3) the only major differences between the two Classifications is the matter of the classification of neoplasms. It should be mentioned that in Egypt the three major causes of blindness are acute ophthalmia, trachoma, and glaucoma. The ophthalmia is due to a nonvenereal gonococcus.

The site selected for the proposed project is in the Governorate of Giza. There are some 26 governorates in Egypt, each representing the equivalent of one of our American States. Part of the Giza Governorate which borders on Cairo will be included. This will include somewhat less than a third of the population of Giza City, which is right across the Nile River from Cairo. This part of Giza City will constitute the urban part of our project population and includes approximately 105,000 people. In addition, there will be 22 villages constituting the rural part which will contribute approximately 167,000 people.

It is hoped that ultimately this project will encompass the help of staff members not only in the Ministry of Scientific Research of which the Medical Research Council is a part, but also the Ministry of Public Health, and the Ministry of Social Affairs. Although there are existing health centers and hospitals in the area selected for the project, the data in these centers and hospitals will not be utilized because of their apparent unreliability. The collection of new data and ophthalmological information will be by new examination by ophthalmologists using standard forms, a new definition of blindness, that is, visual acuity of 6/60 or worse in the better eye with best correction, or where vision is better than that, a 20° or worse limitation in the visual field. It is expected that the project would run about 3 years.

As currently envisaged, there will be three phases to the study. The first phase will include a sample survey of the visual acuity of the population in the Giza area selected for the project and will give us baseline prevalence rates of blindness. It is believed that a sample of 10,000 persons randomly selected would be adequate although the size of the sample is still subject to revision. This will consist of approximately 5,000 from the urban area and 5,000 from the rural area. A number of individuals, not necessarily physicians, will be trained in the use of a portable visual screener to do the sample survey, giving visual acuity tests to those who fall into the sample. A sampling procedure will be designed to meet the specified needs of the study. The individuals who will do the testing in the home will also get information on every-

one tested pertaining to identifying information, demographic data, and whatever social and other information is deemed necessary. Some of the screening will no doubt be done evenings to find heads of the household at home. A concerted effort will be made to test all falling into the sample. Any person picked up in the sample whose visual acuity meets the blindness definition, will then be examined by an ophthalmologist, either at a community health center or a hospital or in the person's home, utilizing a portable ophthalmoscope in order to determine the cause of the severe vision impairment or blindness. The prevalence rates by age, sex, urban and rural, as well as total, achieved in this phase, will be the ones with which to compare similar rates secured in phase two.

The second phase will be started by a publicity campaign and drive to get everyone in the project area, that is, everyone of the 272,000 people, to come in for a visual acuity test voluntarily at either the health centers or the hospitals. Here again, any person picked up in this voluntary screening as blind, will be examined ophthalmologically, either in the center or the hospital or at home. In addition, all agencies serving the blind, hospitals, and clinics, will be canvassed to get information on their known blind. The results from the involuntary or random screening of the sample survey of phase one will be compared with the voluntary screening of the entire population of phase two. The limited size of the phase one sample will permit comparison and, in some cases, determination of, tests of significance for certain aspects of the two populations. Thus, we will have some idea as to which demographic groups by age and sex are not showing up as expected for visual acuity tests and should be of great help in determining how and where to focus educational efforts.

The third phase would be a repeat of the survey sample of phase one. In phase three we would be able to determine crudely some measure of net incidence by comparison with the results of phase one.

Care will be taken in all phases that the reliability of the persons who do the vision testing will be comparable from tester to tester. Simi-

larly, it is important that the reliability of ophthalmologists using the ophthalmoscopes be comparable from one to the other. This study contains the amazing potential of having everyone on the pilot register examined by an ophthalmologist.

As presently visualized, Dr. Soliman would be the principal investigator. Under him would be two control project officers, each of whom is the head of the Department of Ophthalmology in their respective universities in Cairo, namely the University of Cairo and Ein Shams University. Under each of these project control officers would be five ophthalmologists who would be available on a part-time basis to do ophthalmological testing. In addition, there would be a staff of vision screeners who would be trained in the use of portable optical screeners. Furthermore, it is envisaged that the statistical work will be under the direction of the Director of the Statistical Section of the Ministry of Public Health. He will have two assistant statisticians. There will be an IBM installation available for machine processing of the data.

The crude blindness prevalence rate, as determined by the 1960 Egyptian census, was 3.55 persons per thousand population. This rate is about 1.7 times the rate for legal blindness prevalence estimated by Dr. Hurlin for the United States as of July 1960. The disparity is even greater when it is noted that in Egypt a person is considered blind if he cannot see or count the fingers of one hand at a distance of 1 meter. As mentioned above, this corresponds crudely to about 3/200 in our system. I thought it would be interesting to compare some of the data that have become available in the Model Reporting Area with some of the data available through the census for Egypt. I wish to point out the limitations of such comparison and advise you that the comparison is made only in a very crude sense. (1) The difference in definitions, 20/200 against roughly 3/200. As you can see, the Egyptian definition is much more restrictive than ours. (2) The Model Reporting Area represented nine States in 1962 and cannot in any sense be considered a representative sample of the United States. (3) It is quite obvious that when data

become available from Egypt on causes of severe vision impairment and blindness, the distribution of causes will be greatly different from that in the Model Reporting Area States. For one reason, trachoma is a relatively minor cause of blindness in this country, yet it is quite prevalent in Egypt. Ophthalmia is another one that shows a great difference in prevalence in the two countries. (4) The difference between the distributions of ages in the general population is considerable in the two countries. Approximately 38 percent of the MRA general population is under 20 years of age, compared to 51 percent of the Egyptian population. About 30 percent of the MRA general population is 45 years and over, compared to 17 percent of the Egyptian population. The current life expectancy at birth in Egypt is considerably lower than it is in this country. (5) The MRA data are for 1962, the Egyptian census data are for 1960. (6) The data are secured by census in Egypt where a respondent speaks for the family and where there is no medical verification of the census information. (7) The MRA data I am quoting have authenticated visual acuity data in 90 percent of the cases. In the Egyptian data there is no evidence of such authentication.

It should, of course, be evident to all of us that Model Reporting Area data based on reported information are apt to be underreported. The extent of underreporting is not known. I will confine my remarks to the total populations undistinguished by sex because there are no great differences in the prevalence rates between males and females in our country and the same is true in Egypt. Up to age 20, the rates are practically identical for the MRA and Egypt. For the age group 20 to 44, the Egyptian rate is about three times the MRA rate. This is the first age group where we find great differences between the two countries. For the age group 45 to 64, the Egyptian rate is about four and one-half times the MRA rate and increases to over six times the MRA rate for the age group 65 to 74 years. This ratio decreases to about four times the MRA rate for the age group 75 years and over. The total crude Egyptian rate is over twice that for the MRA. I made an attempt to adjust the Egyptian rates crude-

ly for the difference in definitions. Adjusting the Egyptian rates to our definition acts in the direction of approximately doubling their censal total prevalence rate, or if such adjusted rate is compared to the MRA total rate, the ratio is about 4 to 1. Of course, if the rates

were age-standardized, the differences would be even greater, due to the older MRA general population.

I thought you might be interested in these data, but please remember that they are just exercises in crudeness.

APPENDIX F

LIST OF PARTICIPANTS

Third Annual Conference

Model Reporting Area for Blindness Statistics

May 14-15, 1964

State Agencies

Model Reporting Area States¹

Connecticut Board of Education of the Blind:
Genevieve M. Daley, Supervisor, Clerical Section
Cecelia E. Laine, Supervisory Statistician

Kansas Department of Social Welfare:
Marguerite Blase, Medical Social Consultant
Gordon Grabhorn, Administrative Assistant

Louisiana Department of Public Welfare:
William V. Bridges, Director, Division for the Blind
Evalena F. Ford, Medical Social Consultant for Eye Services

Massachusetts Department of Education:
Michael L. Sullivan, Supervisor of Research, Division of the Blind

New Jersey Commission for the Blind:
Mary Elliott, Supervisor, Filing and Registrations
George F. Meyer, Executive Director

North Carolina Commission for the Blind:
Christine Anderson, Supervisor, Social Services Division
Martha Farmer (former registrar)
Mary McColm, Supervisor, Medical Division
Marie Norris, Registrar
H. A. Wood, Executive Secretary
Gertrude Anderson, Field Representative
Thelma Beia, District Medical Supervisor
Florence Bell, District Medical Supervisor
Berta Crumpler, District Medical Supervisor
Carlton F. Edwards, Administrative Officer
Arnold Hyde, Field Representative
Helen Jackson, District Medical Supervisor
Emily Johnston, District Medical Supervisor
Merle Jones, District Medical Supervisor
Elba Kearney, District Medical Supervisor
Gladis Kivett, Field Representative
Marjorie Pearce, Supervisor, Quality Control
Lucile Quinn, District Medical Supervisor

Bernice Roberts, District Medical Supervisor
Betty Jane Smith, Supervisor, Staff Development
Helen Sneeden, Field Representative
Helen Trexler, District Medical Supervisor
Inez B. Wall, Field Representative

Oregon Commission for the Blind:

Grace Sokolow, Social Worker
Clifford A. Stocker, Administrator

Rhode Island Department of Social Welfare:

Eva M. DeTommaso, Office Manager, Division of Services for the Blind

Vermont Department of Social Welfare:
Virginia Cole, Director, Division of Services for the Blind

Non-Model Reporting Area States

California Department of Public Health:
William D. Simmons, Head, Prevention of Blindness Program

District of Columbia Department of Vocational Rehabilitation:
Stephen A. Gambaro, Chief, Division of Services for the Visually Impaired
Clarence Robinson, Registrar, Division of Services for the Visually Impaired

Georgia Department of Education:
W. B. Gaines, Supervisor, Services for the Blind
Dr. A. Polk Jarrell, Director, Division of Vocational Rehabilitation

South Dakota Services to the Blind and Visually Handicapped:
Howard H. Hanson, Director
Lester Konrad, Registrar

Utah Division of Rehabilitation:
Dr. Vaughn L. Hall, Director, Department of Public Instruction
Donald W. Perry, Supervisor, Services for the Visually Handicapped

Virginia Commission for the Visually Handicapped:
Judith Hovatter, Secretary
Dr. D. C. Mac Farland, Director

¹ New Hampshire was unable to send a representative to the Conference due to unavoidable circumstances.

National Voluntary Agencies

United States

American Foundation for the Blind, Inc.:

Dr. Milton D. Graham, Director, Division of Research and Statistics

Dr. Eric Josephson, Research Associate, Division of Research and Statistics

Richard E. Onken, Research Assistant, Division of Research and Statistics

National Society for the Prevention of Blindness, Inc.:

Elizabeth M. Hatfield, Consultant in Statistics

Canada

Canadian National Institute for the Blind:

Dorothy A. Houston, Registrar

Other Agencies

Russell Sage Foundation:

Dr. Robert A. Scott, Associate Sociologist

Catholic Guild for All the Blind:

Reverend Thomas J. Carroll, Executive Director

Dr. Leo H. Riley, Director of Research, American Center for Research in Blindness and Rehabilitation

Universities

Columbia University:

Frank Furstenberg, Jr., Research Associate, Bureau of Applied Social Research

University of North Carolina:

Dr. Dana Quade, Assistant Professor, Department of Biostatistics, School of Public Health

Gallaudet College:

Dr. Jerome D. Schein, Director, Office of Psychological Research

Federal Agencies

Library of Congress:

Charles Gallozzi, Assistant Chief, Division for the Blind

Department of Health, Education, and Welfare:

Welfare Administration:

Garnett A. Lester, Chief, Medical Care Research Group, Division of Program Statistics and Analysis, BFS

National Institute of Neurological Diseases and Blindness:

Irving D. Goldberg, Assistant Chief, Biometrics Branch

Dr. Hyman Goldstein, Chief, Biometrics Branch

C. Morton Hawkins, Jr., Statistician, Biometrics Branch

Herbert C. Henley, Jr., Statistician, Biometrics Branch

Helen B. Moorhead, Medical Record Librarian, Biometrics Branch

Dr. John T. Schwartz, Head, Ophthalmology Projects, Epidemiology Branch

William H. Tolson, Administrative Officer, Collaborative and Field Research

Dr. John B. Wolff, Staff Scientist, Extramural Programs

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